DOCUMENT RESUME

ED 376 623 EC 303 449

TITLE	Hearing on the Reauthorization of the Individuals with Disabilities Education Act (IDEA). Hearing before the Subcommittee on Select Education and Civil Rights of the Committee on Education and Labor. House of Representatives, One Hundred Third Congress, Second Session.
INSTITUTION	Congress of the U.S., Washington, DC. House Subcommittee on Select Education and Civil Rights.
REPORT NO	ISBN-0-16-044876-X
PUB DATE	17 Mar 94
NOTE	87p.; Serial No. 103-78. Parts of the document contain small print.
AVAILABLE FROM	U.S.; Government Printing Office, Superintendent of Documents, Congressional Sales Office, Washington, DC 20402.
PUB TYPE	Legal/Legislative/Regulatory Materials (090)
EDRS PRICE	MF01/PC04 Plus Postage.
DESCRIPTORS	*Disabilities; Educational Legislation; Elementary Secondary Education; Federal Legislation; Hearings; Opinions; Organizations (Groups); *Parent Attitudes; *Parent Participation; *Parent Role
IDENTIFIERS	Congress 103rd; *Individuals with Disabilities Education Act; Reauthorization Legislation

ABSTRACT

This transcript of a Congressional House hearing on the reauthorization of the Individuals with Disabilities Education Act focuses on the role of parents of 5 million schoolchildren with disabilities and ways to strengthen their involvement in their children's education. The transcript includes presented and/or prepared statements from: Cass Ballenger, Representative from North Carolina; Major R. Owens, Representative from New York; Dee Spinkston, Federal for Children with Special Needs; a number of parents of children with disabilities; and representatives of such organizations as the ACTION coalition, the New York Institute for Special Education, and the National Alliance for the Mentally Ill. (DB).

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HEARING ON THE REAUTHORIZATION OF THE INDIVIDUALS WITH DISABILITIES EDUCATION ACT (IDEA)

ED 376 623

HEARING

BEFORE THE

SUBCOMMITTEE ON SELECT EDUCATION
AND CIVIL RIGHTS

OF THE

COMMITTEE ON EDUCATION AND LABOR
HOUSE OF REPRESENTATIVES

ONE HUNDRED THIRD CONGRESS

SECOND SESSION

HEARING HELD IN WASHINGTON, DC, MARCH 17, 1994

Serial No. 103–78

Printed for the use of the Committee on Education and Labor

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82-339 CC WASHINGTON : 1994

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Superintendent of Documents, Congressional Sales Office, Washington, DC 20402
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HEARING ON THE REAUTHORIZATION OF THE INDIVIDUALS WITH DISABILITIES EDUCATION ACT (IDEA)

THURSDAY, MARCH 17, 1994

HOUSE OF REPRESENTATIVES,
SUBCOMMITTEE ON SELECT EDUCATION
AND CIVIL RIGHTS,
COMMITTEE ON EDUCATION AND LABOR,
Washington, DC.

The subcommittee met, pursuant to notice, at 9:38 a.m., Room 2261, Rayburn House Office Building, Hon. Major R. Owens, Chairman, presiding.

Members present: Representatives Owens, Ballenger, and Scott.

Staff present: Maria Cuprill, Wanser Green, John McClain, Morris Turner, and Hans Meeder.

Chairman OWENS. Please be seated. The hearing of the Subcommittee on Select Education and Civil Rights is now in session. Today's hearing is on the reauthorization of the Individuals with Disabilities Education Act.

School reform is the vehicle which should be used to ensure that educators and parents are full partners at the conference table when it is time to implement this reauthorization. This process will offer parents a unique opportunity to demand that their representatives legislatively guarantee their children a real opportunity to learn.

In study after study, it is abundantly clear that parental involvement is key in the child's educational process and significantly influences the quality of the education received by the child. This dialogue has also been credited for increasing the opportunity for the successful integration of that child in the community as an educated adult.

For the 5 million schoolchildren with disabilities, it is essential that their parents be directly involved in a process that will provide them with the skills and knowledge to advocate for the implementation of educational programs stemming from school reform.

Sadly, the Federal, State, and local entities have overlooked the expertise of parents and have strayed from the promise of ensuring full partnership for parents whose children require special education services. Educators frequently view parents as distractions from serious professional discussions.

Studies and testimony from parents often indicate that significant amounts of administrative time and talent are used to erect barriers which promote the disenfranchisement of parents. Most

tragically, it is the 5 million schoolchildren with disabilities who pay the highest price for the growing schism between their parents and special education authorities.

Parents who are already burdened by discrimination and ill-informed by design, reluctantly surrender their children to a woefully inadequate system of special education services. Well-informed parents who combine their efforts with advocates to challenge the system are viewed by the educational establishment as adversaries. It is obvious that an educational system whose actions generate the hostilities of large numbers of parents is a malfunctioning educational system.

We must hold the entire governmental system, including legislators and Federal, State, and local education agencies, accountable for failing to fulfill the promise of partnership for the parents of schoolchildren with disabilities.

We must ensure that the concerns of parents drive the design and implementation of special education programs and that parents are not driven away because they question too much. Our parents must be welcomed as advocates and not scorned as adversaries.

[The prepared statement of Hon. Major R. Owens follows:]

STATEMENT OF HON. MAJOR R. OWENS, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF NEW YORK

School reform is the vehicle which should be used to ensure that educators and parents are full partners at the conference table when it is time to implement this reauthorization. This process will offer parents a unique opportunity to demand that their representatives legislatively guarantee their children a real opportunity to learn.

In study after study, it is abundantly clear that parental involvement is key in the child's educational process and significantly influences the quality of the education received by the child. This dialogue has also been credited for increasing the opportunity for the successful integration of that child in the community as an educated adult. For the 5 million schoolchildren with disabilities, it is essential that their parents be directly involved in a process that will provide them with the skills and knowledge to advocate for the implementation of educational programs stemming from school reform.

Sadly, the Federal, State, and local entities have overlooked the expertise of parents and have strayed from the promise of ensuring full partnership for parents whose children require special education services. Educators frequently view parents as distractions from serious professional discussions. Studies and testimony from parents often indicate that significant amounts of administrative time and talent are used to erect barriers which promote the disenfranchisement of parents. Most tragically, it is the 5 million schoolchildren with disabilities who pay the highest price for the growing schism between their parents and special education authorities. Parents who are already burdened by discrimination and ill-informed by design, reluctantly surrender their children to a woefully inadequate system of special education services. Well-informed parents who combine their efforts with advocates to challenge the system are viewed by the educational establishment as adversaries. It is obvious that an educational system whose actions generate the hostilities of large numbers of parents is a malfunctioning educational system.

We must hold the entire governmental system, including legislators and Federal, State, and local education agencies—accountable for failing to fulfill the promise of partnership for the parents of schoolchildren with disabilities. We must ensure that the concerns of parents drive the design and implementation of special education programs and that parents are not driven away because they question too much. Our parents must be welcomed as advocates, and not scorned as adversaries.

Chairman OWENS. I yield to Mr. Ballenger for an opening statement.

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STATEMENT OF HON. CASS BALLENGER, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF NORTH CAROLINA

Mr. BALLENGER. Thank you, Mr. Chairman. I really would like to thank you for conducting today's hearing on the Individuals with Disabilities Education Act, and I would like to give a special welcome today to Jeanne Gerhardt from Hickory, North Carolina, and I don't know whether she's in the room yet—oh, good girl. Glad to have you aboard.

It's very appropriate for one of our first hearings on IDEA reauthorization that we have invited parents to tell their stories to Congress. To many of us here in Washington passing laws is just an exercise in the legislative process, but to moms and dads across America who are trying to help their child with a disability to get the best education possible, what we do here is crucial.

In education today, parents are our greatest, but most often forgotten resource. We talk on and on about teachers, principals, and school finance, testing, and community partnerships. Sometimes we might remember to mention parents, but when it comes to actually implementing these programs, it seems so difficult for parents to be involved.

We aim so many of these programs at kids whose parents aren't involved, or don't seem to care, or aren't capable of providing a solid, encouraging, enriching home life. But as well-intentioned as these programs are, they make it hard on parents who do care, who do want to help, to be actually involved.

We keep parents at arm's length and don't give them the respect they deserve. But to the children, parents are the first teacher, the first principal, and their best advocate. And the involvement of the parents is the best indicator of whether a child will do well or poorly in school.

For parents of children with disabilities, their experience with school can be even worse. It's tough enough to deal with your child's disability, but these parents have to face a team of special educators and school administrators speaking in medical jargon and making important decisions about the future of their child. I have heard stories of placement systems that seem to be designed to intimidate parents and keep them out of the decisionmaking process.

We must find ways during this reauthorization to make special education a more "parent friendly" and "child centered" system. We should look for ways to solve disputes without always resorting to costly and contentious litigation. And we should make sure that parents get all the information and training that they need to make informed choices and be full participants in their child's education.

I also would like to emphasize the priorities for IDEA that I pointed out at the last hearing.

First, address the "Unfunded Mandate" by increasing the funding up to $1 billion over three years for the Grants to the States program; improve the discretionary programs so that they actually help States and school districts in meeting their responsibilities; to streamline the discretionary programs and move more money into the Grants to the States program; finding more flexible ways for

school districts to operate their programs; and, finally, provide better technical assistance to the States and local districts.

In summary, I'm committed to working with you, Chairman Owens, and the administration in finding the best, most creative solutions to improving this law and the quality of education for students with disabilities. Thank you, Mr. Chairman.

[The prepared statement of Hon. Cass Ballenger follows:]

STATEMENT OF HON. CASS BALLENGER, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF NORTH CAROLINA

Mr. Chairman. I would like to thank you for conducting today's hearing on the Individuals with Disabilities Education Act. I'd like to give a special welcome today to Jeanne Gerhardt who has joined us from Hickory, North Carolina.

It is very appropriate that for one of our first hearings on the IDEA reauthorization, we have invited parents to tell their stories to Congress. To many of us here in Washington, passing laws is just an exercise in the legislative process. But to moms and dads across America who are trying to help their child with a disability to get the best education possible, what we do here is crucial.

In education today, parents are our greatest, but most often forgotten, resource. We talk on and on about teachers, principals, school finance, testing, and community partnerships. Sometimes we might remember to mention parents. But when it comes to actually implementing these programs, it seems so difficult for parents to be involved.

We aim so many of these programs at kids whose parents aren't involved, or don't seem to care, or aren't capable of providing a solid, encouraging, enriching home life. But as well-intentioned as these programs are, they make it hard on parents who DO care, who DO want to help, to be actually involved. We keep parents at arm's length, and don't give them the respect they deserve.

But to the children, parents are their first teacher, their first principal, and their best advocate. And the involvement of parents is the best indicator of whether a child will do well or poorly in school.

For parents of children with disabilities, their experience with school can be even worse. It's tough enough to deal with your child's disability, but these parents have to face a team of special educators and school administrators speaking in medical jargon and making important decisions about the future of their child. I've heard stories of placement systems that seem designed to intimidate parents and keep them out of the decisionmaking process.

We must find ways during this reauthorization to make special education a more "parent friendly" and "child centered" system. We should look for ways to solve disputes without always resorting to costly and contentious litigation. And we should make sure that parents get all the information and training they need to make informed choices and be a full participant in their child's education.

I also want to emphasize the priorities for IDEA that I pointed out at the last hearing.

- Address the "Unfunded Mandate" by increasing the funding up to $1 billion over three years for the Grants to the States program;
- Improve the discretionary programs so they actually help States and school districts in meeting their responsibilities;
- Streamline the discretionary programs and move more money into the Grants to the States program;
- Finding more flexible ways for school districts to operate their programs; and,
- Provide better technical assistance to the States and local districts.

In summary, I'm committed to working with Chairman Owens and the administration in finding the best, most creative solutions to improving this law and the quality of education for students with disabilities.

Chairman OWENS. Thank you. The Chair would like to note that one of our members, Mr. Scott, was here earlier and had to leave for another hearing, and would like to have his opening statement entered into the record. Without objection, we'll enter Mr. Scott's statement into the record.

[The prepared statement of Hon. Robert C. Scott follows:]

STATEMENT OF HON. ROBERT C. SCOTT, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF VIRGINIA

Thank you Mr. Chairman.

I am pleased to join you in opening this hearing on reauthorizing the IDEA program. This is a vitally important program to my constituents and to the Nation as a part of our efforts to ensure that all our children have the opportunity to reach their full potential as citizens. Yet, I am mindful that there are significant issues and problems to be addressed for this program to meet the promise of that opportunity for our children.

At our hearing on the reauthorization two weeks ago, Mr. Chairman, you identified the critical problems of the shortage of qualified special education teachers and support staff, and the overrepresentation of poor minorities in the most restrictive special education programs due to the practice by school systems of shuttling such students out of regular classroom settings. Witnesses at that hearing further detailed these problems, identified others and suggested solutions. Mr. Chairman, I applaud your stalwart dedication and determination to address these problems and I look forward to working with you toward that end.

Today, we will hear from two panels of experts who can give us first-and knowledge and advice on the issues we must address. I am proud to note that one of those experts is our own Sharon Retos from Hampton, Virginia, a part of the 3rd District which I represent. It is my pleasure to welcome you Ms. Retos. Unfortunately, it is necessary that I divide my time between this important matter and other vitally important issues under consideration before two other committees on which I serve. Please excuse me, but know that I will be working closely with you, Mr. Chairman, and the other members of the committee, as we move forward to reauthorize a revitalized IDEA program.

Chairman OWENS. I would also like to note that, due to the request of large numbers of parents that we could not accommodate today, we will be holding, in the future, an open mike hearing and inviting all parents who want to testify, with a longer period of time to allow the greater variety of parents with different viewpoints to get on the record. We'll schedule that hearing at some time between now and July.

Our first panel consists of Ms. Dee Spinkston, Federation for Children with Special Needs, from Boston, Massachusetts.

Before we begin, I would like to ask if there's anyone in the room that needs the services of an interpreter. Thank you. You may begin, Ms. Spinkston.

STATEMENT OF DEE SPINKSTON, FEDERATION FOR CHILDREN WITH SPECIAL NEEDS, BOSTON, MASSACHUSETTS3

Ms. SPINKSTON. Mr. Chairman and Congressman Ballenger, thank you for the invitation to come and testify before you on the reauthorization of the Individuals with Disabilities Act. As the sister of a young man with severe learning disabilities, and an advocate for other parents and children with disabilities, I consider this opportunity an honor.

The IDEA has brought about significant changes that have positively changed the lives of children with disabilities and their families. Before its inception, families lacked the basic assurance of a free and appropriate education for their children.

Once these assurances were guaranteed by law, provisions were established for the meaningful and informed participation and involvement of parents through the establishment of Parent Training Information Projects, now funded in each State, which promoted that involvement.

Subsequent amendments required States to formally address the issues surrounding transition from school to work of young adults

with disabilities and new advances in assistive technology have allowed students to surpass prior expectations and now be included in Individualized Education Plans.

The need for traditionally underserved communities to have access to support to help them access quality information and quality special education programs services, as well as community-based support, is directly addressed by the experimental projects. These firm commitments have been followed by the movement toward education reform.

IDEA is not static, but rather designed to grow and change with the ever-evolving needs of those people served by this legislation. We must constantly examine and evaluate its ability to respond to issues that impact our children with disabilities, as well as our children without disabilities.

A current concern that is widespread is the lack of enforcement of compliance with the procedural safeguards as established by law. The law must make provision for resources to support extensive monitoring activities by the Office of Special Education and Rehabilitative Services. The power of State education agencies to enforce infractions of compliance on local education agencies must be strengthened.

The Office of Special Education and Rehabilitative Services must develop new investigative techniques to gain information that will help them correctly analyze and uncover systemic barriers to parent access and develop effective remedial plans that will bring States into compliance and follow-up to ensure compliance is gained.

State and local education agencies should be more thoroughly required to document their efforts to inform parents about the complaint management system, procedural safeguards, rights, and ensure that the systems are accessible to all parents of children with disabilities, particularly those from traditionally underserved communities and for whom English is not a first language.

Currently, for schools that are in constant violation of procedural safeguard of parents, essentially what they get is a pretty severe talking to, very often, by school departments and, at worst, a slap on the wrist. There's actually very little done to make it prohibitive for schools to violate parents' rights and procedural safeguards.

OSERS must also investigate the impact that State and national school reform efforts will have on students with special needs and investigate the extent to which some school reform efforts will affect disabled children, both positively and negatively.

For example, the Technical Assistance for Parent Programs receives reports at its central office very often that the dramatic increases in the suspension and expulsion of students with special needs has been linked to disciplinary provisions of school reform efforts in several States.

The low expectations of, particularly, minority children, which leads to the overreferral and inappropriate placement in special education, may also be the cause of very poor outcomes for our students with disabilities.

I remember my own experience with my brother Michael, who at the time was 12 years old, sitting at his third IEP meeting with the teacher trying to explain to me why at age 12 and after three

years of special education, he was still only reading at the beginning first-year level.

When I questioned her about that, she assured me, "It's certainly just because he has a severe learning disability." And when I questioned her about what a learning disability means—he learns differently, not that he can't learn at all—what she said was, "Your expectations for him are much too high. There's not a child Michael's age in all of Boston public schools who's reading on grade level."

I surely suspect that this is part of the reason that with many of our children with disabilities who are receiving special education, we're not having the outcomes we would like to see after years in special education.

The reauthorization of IDEA should examine State and national school reform initiatives, which should complement and strengthen the education of all students, not weaken or interfere with entitlements of students with disabilities and their families.

With the advent of the movement toward full inclusion, it's extremely important for all potential team participants who would be involved with the inclusive education of a child with a disability to have access to support and training to ensure a successful, inclusive education where students with disabilities will be educated in the mainstream.

Statutory and regulatory barriers which may impede support for training and support all of a child's team members must be eliminated. For example, funds designated for the training of special education teachers under part B of the Act can no longer be reserved solely for the training of teachers with special education certifications.

With the diminishing resources in education, it is incumbent upon special education to support the training of regular teachers who will be working cooperatively with special educators to ensure the responsible and appropriate inclusion of infants, toddlers, children, youth, and young adults with special needs in the mainstream.

Finally, increased funding to support the expansion of parent training, information, and peer support is crucial. There are a myriad of issues from education reform and early intervention to inclusion and the use of assistive technology which PTI projects must themselves learn more about in order to address it for parents in their State.

As the first line of contact for many parents in their State, they will need additional technical assistance and funds to help parents address developing cutting-edge issues in education.

There is also a great need to expand the scope and funding of the experimental project initiative, which provides technical assistance to neighborhood- and community-based parent support information projects. Technical assistance to those projects needs to be expanded as well as independent funding for the projects under part D.

The continuing struggle to develop and deliver support services in traditionally underserved communities is an area of need. That cannot be ignored in increasingly culturally diverse America. Thank you.

[The prepared statement of Charlotte Spinkston follows:]

STATEMENT OF CHARLOTTE "DEE" SPINKSTON, EXPERIMENTAL PROJECT COORDINATOR, TECHNICAL ASSISTANCE FOR PARENT PROGRAMS [TAPP] PROJECT, BOSTON, MASSACHUSETTS

Mr. Chairman, and members of the Subcommittee on Select Education and Civil Rights. Thank you for your invitation to come and testify before you on the reauthorization of Individuals with Disabilities Education Act [IDEA]. As the sister of a young man with disabilities and an advocate for other citizens with disabilities, I consider this opportunity as an honor.

IDEA has brought about significant changes that have positively changed the lives of children with disabilities and their families. Before its inception, families lacked the basic assurance of a free and appropriate education for their children. Once these assurances were guaranteed by law, provisions were established for the meaningful and informed involvement of parents, and Parent Training Information [PTI] Projects were funded in each State to assist in promoting that involvement. Subsequent amendments required States to formally address the issues surrounding transition of young adults with disabilities from school to work, and new advances in assistive technology that have allowed students to surpass prior expectations may now be included in Individualized Education Plans [IEPs]. The need for traditionally underserved communities to have access to support to help them access quality information on quality special education programs services and community-based support is directly addressed by the experimental project initiative. These firm commitments have been followed by the movement toward education reform.

IDEA is not static, but rather designed to grow and change with the ever-evolving needs of those people served by this legislation. We must constantly examine and evaluate its ability to respond to issues that impact our children with disabilities, as well as those without disabilities as well.

A current concern is the lack of enforcement of compliance with procedural safeguards as established by law. The law must make provision for resources to support extensive monitoring activities by the Office of Special Education and Rehabilitative Services [OSERS]. The power of State education agencies to enforce infractions of compliance on the local education agency level must be strengthened. The Office of Special Education and Rehabilitative Services must develop new investigative techniques to gain information that will correctly analyze and uncover systemic barriers to parent access and develop effective remedial plans that will bring States into compliance. State and local education agencies must document their efforts to inform parents about the complaint management systems and procedural safeguards and ensure these systems are accessible to all parents of children with disabilities, particularly those from traditionally underserved communities.

OSERS must also investigate the impact that State and national school reform efforts will have on students with special education needs and investigate the extent to which these efforts will affect disabled children, both positively and negatively. For example, the dramatic increases in the suspension and expulsion of students with special needs has been linked to disciplinary provisions contained in some States school reform legislation [as reported to the TAPP project from PTI projects around the country].

The reauthorization of IDEA should examine State and national school reform initiatives which should complement and strengthen the education of all students and not weaken or interfere with entitlements of students with disabilities and their families.

With the advent of the movement toward full inclusion, it is extremely important for all team participants to have access to support and training to ensure a successful education experience for students who will be educated in the mainstream. Statutory and regulatory barriers which may impede support for training and support all of a child's team members must be eliminated. For example, funds designated for the training of special education teachers under part B of the Act can no longer be reserved solely for the training of teachers with special education certifications. With the diminishing resources in education, it is incumbent upon special education to support the training of regular educators who work cooperatively with special educators to ensure the responsible and appropriate inclusion of infants, toddlers, children, youth, and young adults with special needs in the mainstream.

Finally, increased funding to support the expansion of parent training, information, and peer support is crucial. There are a myriad of issues from education reform and early intervention to inclusion and the use of assistive technology which PTI projects must address. As the first line of contact for many parents in their States, they will need additional technical assistance and funds to do that. There is a great

need to expand the scope and funding of the experimental project initiative. Ongoing technical assistance to developing neighborhood/community-based parent support, information and training projects is needed. The continuing struggle to develop, deliver, and support services in traditionally underserved communities is an area of need that cannot be ignored in an increasingly culturally diverse America.

Chairman OWENS. Thank you. Did I understand you correctly? You said that the teacher said, "There is not a child in Boston reading on grade level?" Do they mean not a child with learning——

Ms. SPINKSTON. Her comment to me was that I was expecting too much for Michael, because there wasn't a child his age in all of Boston public schools who was reading on grade level. So for me to expect a child with severe learning disabilities to be reading on grade level was just too high an expectation.

Chairman OWENS. Yes. You also said, "School reform has led to a dramatic increase in suspensions of children with disabilities?"

Ms. SPINKSTON. In suspensions and expulsions in Massachusetts, as an example—well, in other States as well. The Technical Assistance for Parent Programs has been hearing that information, that school reform efforts in several States are resulting in a large flux of suspensions and expulsions of students with special needs.

Chairman OWENS. There have been no statistics collected on this, however. It's just information that has come in?

Ms. SPINKSTON. I believe PTI projects in those States are collecting statistics, and I can talk with the executive director of the Federation and ask her to obtain that information for your office.

Chairman OWENS. So as school systems move to improve, they are becoming more hostile to children with disabilities, is what one would have to conclude?

Ms. SPINKSTON. I think that's a part of it. There seems to be a resentment that children with special needs sort of have this entitlement and have certain rights that certainly all students should have, but right now it's children with disabilities who have them.

I also think that it's an ignorance of the provisions and rights and entitlements of parents and children who have special needs. I think educators, principals, and teachers, just don't know about those rights.

I advocate on a fairly regular basis for parents, particularly minority parents in the Boston area. I'm frequently surprised at how often teachers and team leaders will give parents inaccurate information about what their rights are under the law.

If the parent questions, "Well, this evaluation says X, but I think I would like an independent evaluation," team leaders and teachers will say, "Well, certainly, Ms. Jones, that is your right as long as you pay for it."

Without an advocate there to say, "Excuse me, but the law is pretty clear that the parent has a right to reject your evaluation and receive an independent one at the school committee's expense." Either they sit back and don't say anything or literally, they just give you a blank look.

I don't think many of our special educators even know the law and understand the entitlements for parents and children under the law.

Chairman OWENS. How long have you been the coordinator for this experimental project?

Ms. SPINKSTON. I have been coordinating this project since 1990.

Chairman OWENS. Do you have any ideas about how we, in this very practical world of limited resources, may better tackle this problem of getting compliance and of giving the parents the tools they need?

Ms. SPINKSTON. What I have found is that the community-based and neighborhood-based nature of these projects have made what I consider a fairly dramatic impact on, first of all, how soon parents are getting information that they need to have to successfully advocate for their children.

In many of the States—Los Angeles, New York, Brooklyn, Detroit and the other States I'm working in, when the projects first opened, a majority of people who began participating in experimental project activities were parents who had children with disabilities who were 9, 10, 11, or teenagers who had been served in special education facilities for some years.

This was the first time they were getting information about their child. Now, four years later, very many of the parents who are being referred to those community-based projects, and who are finding out about them, are parents of infants.

So we're having also a very good impact on parents of very young children and newly diagnosed children. It is certainly very good for parents if they know about their entitlements and their rights earlier in their child's education.

Chairman OWENS. Do you know how much money your project gets?

Ms. SPINKSTON. The experimental project initiative? This year we have $50,000.

Chairman OWENS. This is supposed to accomplish what?

Ms. SPINKSTON. Through those funds I provide technical assistance to eight projects in different States, through small subcontracts of between $3,500 and $5,000. We also provide technical assistance for them and they attend national activities that the TAPP project is responsible for producing.

Chairman OWENS. Do you think it would be useful if we could join the twentieth century and have the funds available for using radio, television, cable television and videos?

Ms. SPINKSTON. I think it would be a wonderful thing. I think to increase funding, both for the funding of experimental projects——

Chairman OWENS. Seriously, do you think we could get parents to know their rights?

Ms. SPINKSTON. Absolutely. I don't have any doubt about that. Just from the small efforts we have been able to implement with the funds we have through the experimental projects, what these parents have been able to do in their own community with very little money is really amazing to me. The way they have been able to rally other organizations in their community to support their cause is incredible.

Chairman OWENS. Do you know of any single instance anywhere in the country where they are using radio or cable television to get out information?

Ms. SPINKSTON. One of the presenters who will be on the panel coming up works a lot with public access television. The project in

New York operates out of Brooklyn, which is United We Stand. The director there is Lourdes Putz. She frequently appears on cable and provides information to parents in an interview forum, sharing information about parent rights.

Also, one of the directors of the experimental projects in the Los Angeles area—her name is Monica Pope, has appeared on cable. Again, in the talk show format, she shares information with parents who have children with disabilities.

Again, one of the panelists coming up as an experimental project participant, part of what she is doing is developing the materials that might be used by PTI projects, as well as other community-based groups, and could also be used on cable, audio tapes, video tapes, as a means of providing information and training to parents.

I think it is an excellent idea and certainly something that would warrant further investigation, given the resources to be able to do that. I think it's an exciting concept.

Chairman OWENS. Given your limited resources, how many parents do you think you reach per year?

Ms. SPINKSTON. Well, all the experimental projects submit reports to me quarterly about their activities. I would say, on average, the experimental projects identify, on an average, about five new parents a month.

There is one project located in Detroit which averages more like 12 new parents per month. Again, these are all minority parents who have children with disabilities. They're all in mostly very poor, underserved communities in inner cities.

Chairman OWENS. I'm aware of the fact that your project was created by our last reauthorization in response to the need to get some special effort going to reach underserved populations. Thank you very much. Mr. Ballenger.

Mr. BALLENGER. I don't have a great deal of questions because I find it quite fascinating. Is your experimental project national?

Ms. SPINKSTON. It is a national project, yes.

Mr. BALLENGER. You're located in Boston and you work out of there?

Ms. SPINKSTON. That's right.

Chairman OWENS. You just serve four States, you mentioned?

Ms. SPINKSTON. No, right now I serve five States. There are three projects that are funded to work in Los Angeles; Louisiana; Detroit, Michigan; Brooklyn, New York; Philadelphia. Well, I guess that's more than six then.

I'm working with a parent group that is located on the Virgin Islands—there's not a PTI project funded on the Virgin Islands. It's an extremely——

Mr. BALLENGER. Do they pay your travel expenses?

Ms. SPINKSTON. Yes, absolutely. They do actually.

Mr. BALLENGER. I don't think you could spread yourself out more thinly than in the States you just named. Is it because the States ask for assistance?

Ms. SPINKSTON. I actually do quite a bit of outreach. In the first year of the project, there was more money in the project, so I did quite a bit of travel, and through a lot of outreach identified several groups in several different States.

As a result of reduction in funding, I now do a lot of maintenance of technical assistance of the projects that were established in the first two years of the project. There *hasn't been a lot of outreach* effort in the last year and a half because there just hasn't been any money for outreach.

Mr. BALLENGER. I'm finished.

Ms. SPINKSTON. Thank you very much.

Chairman OWENS. Just a little consulting about how much your funds were reduced. You got about $150,000 the first year?

Ms. SPINKSTON. The first year.

Chairman OWENS. And now you're down to $50,000 per year?

Mr. BALLENGER. Did we do that?

Ms. SPINKSTON. Last year it was $35,000.

Chairman OWENS. We did not do that. We're the authorizing committee; we're on your side. It's the appropriations committee who did it. That's most unfortunate, and we'll take note of that. Thank you very much.

Ms. SPINKSTON. Thank you.

Chairman OWENS. Our second panel consists of Ms. Deidra Loewe from Los Angeles; Ms. Judy Woods of Los Angeles; Ms. Sharon Retos of Hampton, Virginia; and Ms. Clara Berg from Bayside, New York.

I forgot to point out before that we have copies of the written testimony. You are free at this point to highlight that testimony. Of course, a question-and-answer period will bring out additional points. We'll start with Ms. Loewe.

STATEMENTS OF DEIDRA LOEWE, LOS ANGELES, CALIFORNIA; MS. JULIE WOODS, LOS ANGELES, CALIFORNIA; MS. SHARON RETOS, HAMPTON, VIRGINIA; AND MS. CLARA BERG, BAYSIDE, NEW YORK

Ms. LOEWE. Mr. Chairman and members of the committee, I would like first of all to thank you for inviting me to testify on behalf of my disabled child regarding special education. I consider it an honor and a privilege.

My name is Deidra Loewe. I am from South Central Los Angeles, and a divorced mother of two beautiful children, Brandon, who is 11, and Candace, who is 9.

My youngest child, Candace, was born with a congenital heart defect, tricuspid atresia, which was diagnosed several days after her birth. At that time we were told she would require several surgeries and have special health care needs.

She had her first closed-heart procedure at six weeks. This maintained her condition until she was 10 months.

At that time Candace suffered a severe hypercyanotic spell, which concluded with a full cardiac arrest. She stopped breathing for approximately two to three minutes, but was resuscitated and immediately flown by medical helicopter to the nearest hospital with a surgical team ready for immediate corrective surgery.

She received another closed-heart procedure which was successful; however, the following day she started having serious complications in the form of severe seizures, another cardiac arrest, and renal failure. The general consensus of the neonatal intensive care unit was that she would probably die within 24 hours.

It was like a miracle that she survived this trauma. My marriage, however, did not survive the added strain to our resources, time, and energy. I now find myself alone in the struggle to care for and provide for my children's needs.

Although Candace survived, she had slipped into a semicoma, which she remained in for the following year. She spent her first birthday in the intensive care unit and was discharged after a one-year stay.

I was able to take her home after receiving training on caring for her special needs: tracheostomy care, CPR, gastric-tube feeding techniques, and care. I received in-home supports in the form of infant stimulation and physical and occupational therapy that I feel was excellent.

Later Candace was transitioned to a center-based program at 18 months, and at age 3 was transitioned to public special education. One of my first experiences visiting the school where she was to attend was the Individualized Educational Plan meeting.

I brought along my daughter's physical therapist from the infant program to support me. She was an excellent and caring P.T. We both had serious concerns about the recommendations the IEP team had made: placement in the developmental handicapped program, physical and occupational therapy on a consultive-only basis.

I was completely disillusioned by the whole process. I knew I had the right to give meaningful input; however, it was clear to me that my input was not valued. What I did not know was that I could refuse to sign the IEP if I disagreed with the team's recommendations.

When I made recommendations, I was told, "That is not how we do things here." It seemed to me that they were just going through the motions, but not listening to anything I or my physical therapist had to say.

Needless to say this certainly affected my attitude about future IEP meetings. It seemed pointless and a waste of time because they were going to do what they wanted regardless of my recommendations.

It seemed that the goals were already established prior to the meeting, and I was only wanted to sign their recommendations. This is not how the IEP process is supposed to work. I am aware of that, but that awareness has not changed anything for me.

Due to my frustration with the process, I have not attended the IEPs for the past two years. I am planning, however, to request a new IEP upon my return home in hopes that a more realistic and appropriate plan can be achieved. Moreover, I would like the plan to be implemented and monitored.

It is my hope and dream for both of my children to be educated and reach their personal best. For minority children this is usually a major challenge, but for minority children with disabilities it is usually an impossible dream.

When I asked the school officials at the IEP meeting to coordinate their educational services with medical services located in the same facility, I was told they could do nothing to help me. I found that hard to believe, considering the fact that they only served children in that school and those services were usually delivered in their classrooms.

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I attempted unsuccessfully to receive direct physical therapy for Candace for several years. I was told that Candace was not a good candidate for direct therapy because she was unlikely to walk and needed to display perambulation skills, which she did not possess. At that time Candace could walk with the assistance of a ring walker all over her classroom.

The therapy plan written for her was for physical therapy on a consultive-basis only. What that meant for my child was that the therapy plan was delegated to someone who was unskilled and unable to perform the task.

The physical therapist, however, was paid for services rendered but not received, and I was told that I was unable to send her elsewhere for therapy because that would be a duplication of service. How can duplication of service occur when the child is not receiving any service?

I began to wonder if the majority culture was experiencing these difficulties. I became angry and depressed by the whole situation. Fighting the service delivery system had become more overwhelming than the physical condition of my child.

To me the therapy was a primary educational goal since Candace has no self-help skills and these skills were dependent on her ability to move. Therapy can also help maintain a person with a disability and prevent further impairments.

I would like to add that the program that my child was placed in is, in essence, is a glorified day care center where low-functioning children are warehoused and where education is seldom even attempted.

The goals the school staff recommended were impossible to achieve without addressing her orthopedic concerns, and I cannot recall the school ever mentioning anything about alternative communication or any other educational hopes for her.

It was apparent at the first IEP I attended that my hopes and dreams for my child were considered to be unreasonable and unacceptable, not to mention unobtainable. My hopes and dreams for both of my children have not ended, but in my daughter's case I cannot project too far into the future.

I truly do not know how many tomorrows we shall share together; all we have is today. The special education system is failing Candace and many other children like her. They are entitled to an education that they simply are not receiving.

[The prepared statement of Deidra Loewe follows.]

STATEMENT OF DEIDRA LOEWE, LOS ANGELES, CALIFORNIA

Mr. Chairman and members of the committee, I would first of all like to thank you for inviting me to testify on behalf of my disabled child regarding special education. I consider it an honor and a privilege.

My name is Deidra Loewe. I am from South Central Los Angeles, and a divorced mother of two beautiful children, Brandon, who is 11, and Candace, who is 9. My youngest child, Candace, was born with a congenital heart defect [Tricuspid Atresia], which was diagnosed several days after her birth. At that time we were told she would require several surgeries and have special health care needs. She had her first closed-heart procedure at six weeks. This maintained her condition until she was 10 months. At that time Candace suffered a severe hypercyanotic spell, which concluded with a full cardiac arrest. She stopped breathing for approximately two to three minutes, but was resuscitated and immediately flown by medical helicopter to the nearest hospital with a surgical team ready for immediate corrective surgery. She received another closed-heart procedure which was successful; however, the fol-

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lowing day she started having serious complications [severe seizures, another cardiac arrest, and renal failure]. The general consensus of the neonatal intensive care unit was that she would probably die within 24 hours. It was like a miracle that she survived all this trauma ... my marriage, however, did not survive this added strain to our resources, time, and energy. I now find myself alone in the struggle to care for and provide for my children's needs. Although Candace survived, she had slipped into a semicoma, which she remained in for the following year. She spent her first birthday in the intensive care unit and was discharged after a one-year stay. I was able to take her home after receiving training on caring for her special needs: [tracheostomy care, CPR, gastric-tube feeding techniques and care]. I received in-home supports [infant stimulation in the form of physical and occupational therapy] that I feel was excellent. Later Candace was transitioned to a center-based program at 18 months, and at age 3 was transitioned to public special education.

One of my first experiences visiting the school where she was to attend was for the Individualized Educational Plan [IEP] meeting. I brought along my daughter's physical therapist from the infant program to support me. She was an excellent and caring P.T. We both had serious concerns about the recommendations the IEP team had made [placement in the developmental handicapped program, physical and occupational therapy on a consultive-only basis]. I was completely disillusioned by the whole process. I knew that I had the right to give meaningful input, however, it was made clear to me that my input was not valued. What I did not know was that I could refuse to sign the IEP if I disagreed with the team's recommendations. When I made recommendations, I was told, "That is not how we do things here." It seemed to me that they were just going through the motions, but not listening to anything I or my daughter's physical therapist had to say. Needless to say this certainly affected my attitude about future IEP meetings. It seemed pointless and a waste of time, because they were going to do what they wanted regardless of my recommendations. It seemed that the goals were already established prior to the meeting, and I was only wanted to sign their recommendations. This is not how the IEP process is supposed to work. I am aware of that, but that awareness has not changed anything for me. Due to my frustration with the process, I have not attended the IEPs for the past two years. I am planning, however, to request a new IEP upon my return home in hopes that a more realistic and appropriate plan can be achieved; moreover, I would like the plan to be implemented and monitored. It is my hope and dream for both of my children to be educated and reach their personal best. For minority children this is usually a major challenge, but for minority children with disabilities it is usually "the impossible dream." When I asked the school officials at the IEP meeting to coordinate their educational services with medical services located in the same facility, I was told they could do nothing to help me. I found that hard to believe, considering the fact that they only served children in that school and those services were usually delivered in their classrooms. I attempted unsuccessfully to receive direct physical therapy for Candace for several years. I was told that Candace was not a good candidate for direct therapy because she was unlikely to walk and needed to display perambulation skills which she did not possess. At that time Candace could walk with the assistance of a ring walker all over her classroom. The therapy plan written for her was for physical therapy on a consultive basis only. What that meant for my child was that the therapy plan was delegated to someone who was unskilled and unable to perform the task due to other job responsibilities. The Physical Therapist, however, was paid for services rendered but not received, and I was told that I was unable to send her elsewhere for therapy because that would be duplication of service. But how can duplication of service occur when the child is *not* receiving any service? I began to wonder if the majority culture was experiencing these difficulties. I became angry and depressed by the whole situation. Fighting the service delivery system had become more overwhelming than the physical condition of my child. To me the therapy was a primary educational goal since Candace has no self-help skills and these skills are dependent on her ability to move. Therapy can also help maintain a person with a disability and prevent further impairments. I would like to add that the program that my child was placed in is, in essence, a glorified day care center where low-functioning children are warehoused and where education is seldom even attempted. The goals the school staff recommended were impossible to achieve without addressing her orthopedic concerns, and I cannot recall the school ever mentioning anything about alternative communication or any other educational hopes for her. It was apparent at the first IEP I attended that my hopes and dreams for my child were considered to be unreasonable and unacceptable, not to mention unobtainable. My hopes and dreams for both of my children have not ended, but in my daughter Candace's case I cannot project too far into the future ... I truly do not know how many tomorrows we shall share together; all we have is today. The special edu-

cation system is failing Candace and many other children like her. They are entitled to an education that they simply are not receiving.

Chairman OWENS. Thank you. Ms. Woods.

Ms. WOODS. Mr. Chairman and Congressman Ballenger, I would like to thank you for giving me the opportunity, as a parent, to testify on behalf of children with disabilities. This is a great honor and a privilege.

Imagine listening to music, everything is calm, and all of a sudden a rage builds up inside your child and the next thing you know, he or she starts kicking, hitting, knocking things over, and breaking things. What do you do?

Now imagine a cozy evening at home, relaxing on the couch with your child, and all of a sudden the child reaches across, slaps you, grabs you, and bites you. By the time you've calmed yourself, he's as calm as a warm summer breeze and acts as if nothing has happened. What do you do?

My name is Julie Woods and I am a divorced single parent, and the child I am talking about is my son, Victor Cooper. He is 11 years old and was born with autistic cerebral palsy.

Cerebral palsy is a condition caused by brain damage, usually occurring during, before, or shortly following birth. Cerebral refers to the brain, and palsy is the disorder of movement and posture.

It is not curable in an accepted sense, although education, therapy, and applied technology can help people with cerebral palsy lead positive lives. It is not a disease and should never be referred to as such. It can range from the mild to the severe.

Autism is a neurological disorder that alters his physical sensations and ability to relate to the rest of the world; the immune system, which usually helps the body fight diseases, often goes haywire in people with autism.

The other night I was sitting next to my son reading, and out of the blue, for no reason whatsoever, he started crying uncontrollably. All I could do was look down into his pretty brown eyes, hold him, and say, "Everything will get better."

How can I know whether everything really will get better? Victor does not have any verbal skills; I have a child that cannot communicate. I am a mother, and I can't imagine what it is like for him not to be able to tell someone something is wrong or something hurts inside. His lack of communication skills makes it hard to understand what he thinks and how he sees himself.

I know there are no guarantees and nothing is promised to any one of us in this vast universe, but not being able to imagine what it would be like to see him as an adult is scary. You have to be willing to wear—I'm nervous. Excuse me.

Chairman OWENS. No, don't worry. Take your time.

Ms. WOODS. Okay. You have to be willing to wear many hats to raise a child with a disability. You are sometimes an educator, an advocate, a doctor, a psychiatrist, or even a gymnast, and that's to keep up. The most important hat is that of a parent.

In the beginning it's as if you are out there all alone, trying to do this impossible task of raising a child with special needs. And it seems like no one is in your situation. I would ask myself, "Where can I go, where are there others like me?"

I live in Los Angeles, California, in the part of town called South Central. When I found out that Victor was disabled, I tried to find a parent support group. I knew in my heart there was one out there somewhere, it just didn't seem like there was one in my neighborhood.

Lo and behold, one day William Deshay, a service coordinator at the *Regional Center*—it's an agency for disabled people—informed me that there was a support group located in South Central, and it's called Loving Your Disabled Child, L-Y-D-C. This is Monica Pope. She runs this one, I think. One of the other ladies mentioned her.

When I called, it was as if a weight was lifted off of my soul. I could not believe, after feeling alone for so long, that there was other families of color out there with children with disabilities. At this time, my son was nine years old.

No one should have to wait nine years for anything. I had almost given up hope, and for a single parent, hope is sometimes all you have. Being forced to give up on all you have is sometimes hopeless; I was so excited and afraid at the same time. LYDC gave me hope, faith, an empowerment, and a sense of belonging, whereas at first I felt like I was the only one out there.

When you are a single parent with a child with a disability, you have to be strong, and no one should see you cry. You feel as if no one should see you cry or see you hurt inside for your child.

You can't have a weakness, show guilt in any way, or society reacts with pity for your child. But in all actuality, there is nothing to feel guilty or ashamed about. Nevertheless, the feeling is there.

There are many nights I sat up staring out the window and saying to myself, "This is hard. I'm tired." Somehow I had—the strength comes out from nowhere. I thank God for parent support groups like LYDC.

This year nearly 100,000 women will become mothers of disabled children. You can't—I can't conceive of 100,000 parents feeling as if there was no way to handle the job in front of them. Raising a child with a disability is a job, and I have 11 years of experience at it.

I have worked hard at fighting for my son's rights, harder than being in a boxing ring with Mike Tyson. Tyson couldn't have hit me harder than getting hit with the fact that my son would not get a normal education. How was Victor going to get the kind of education he needed?

My son has never called me "mamma," and yet I hope—I just can't—I just don't have the skills to teach him to say "mamma." I had no idea I could give my input as to my son's education until I went to the support group, LYDC. The school board had never told me I could come down and have input.

There was a workshop at LYDC on the Individuals with Disabilities Act, which is IDEA, and the IEP, Individual Education Plan.

After the workshop, I wondered if Victor's education plan was really individualized. I thought back to his last IEP meeting. Is Victor actually getting an individualized education?

Let me see. At the last IEP I was told they didn't have a speech therapist that could work with him or a behavioral therapist, and there was nowhere else he could be placed in the school system

that could provide for his needs. You tell me, is he receiving an individualized education?

Fact: After I completed the LYDC workshop, I was able to use that knowledge I gained. I was able to prevent my son from being expelled due to behaviors associated with his disability and get him a special personal aide. This was the first time I played a major part *in my son's education, and I am looking forward to my next* part.

I am also a college graduate with a BA in accounting, but yet I don't know how to teach my son how to function in society. It's not for the lack of scholastic education; I have that. But what I don't have is training on how to teach my son with a learning disability.

At the present time, there are no classes, programs, or training centers other than the one LYDC in my community which offers training to people with children with disabilities. I think to empower parents with the knowledge it takes to teach their special children should be the first step.

If you have a typical child that is behind in math, English, history, you can buy the book and tutor him or her at home. But who tutors the child with the disability? I don't think there will be one solid solution, but if we work together to empower each other—I mean, the professionals and the parents—no one would feel as hopeless or helpless for the future of our disabled as we do.

I think when Victor started crying uncontrollably, in his own way he was asking me, "Mommy, what do I do?"

[The prepared statement of Julie R. Woods follows:]

STATEMENT OF JULIE R. WOODS, LOS ANGELES, CALIFORNIA

Mr. Chairman, members of the committee. I would like to thank you for giving me, a parent, this opportunity to testify on behalf of children with disabilities. This is a great honor and a privilege.

Imagine listening to music, everything is calm, and all of a sudden a rage builds up inside your child and the next thing you know, he or she starts kicking and hitting, knocking over things, and breaking things. What do you do? Now imagine a cozy evening at home, relaxing on the couch with your child. All of a sudden your child reaches across and slaps you, grabs you by the hair and bites you. By the time you calmed yourself, he's as calm as a warm summer breeze and acts as if nothing has happened. What do you do?

My name is Julie Woods and I am a divorced single parent and the child I am talking about is my son, Victor Miguel Cooper Jr. He is 11 years old and was born with Autistic Cerebral Palsy. Cerebral palsy is a condition caused by damage to the brain, usually occurring before, during, or shortly following birth. "Cerebral" refers to the brain, and "palsy" to a disorder of movement or posture. It is not "curable" in the accepted sense, although education, therapy, and applied technology can help persons with cerebral palsy lead productive lives. It is not a disease and should never be referred to as such. It can range from mild to severe. Autism is a neurological disorder that alters his physical sensations and ability to relate to the rest of the world. The immune system, which usually helps the body fight off disease, often goes haywire in people with autism. The other night I was sitting next to my son reading, and out of the blue, for no reason whatsoever, he started crying uncontrollably. All I could do was look down into his pretty brown eyes, hold him, and say, "Everything will get better." But how can I know whether everything really will get better? Victor does not have any verbal communication skills. I have a child who cannot communicate, I am a mother, and can't imagine what it is like for him not to be able to tell someone, when something is wrong or when he hurts inside. His lack of communication skills makes it hard to understand what he thinks or how he sees himself. I know there are no guarantees and nothing is promised to any one of us in this vast universe, but not being able to imagine what he will be like as an adult is scary.

You have to be willing to wear many hats to raise a child with a disability. You are sometimes an educator, an activist, a doctor, a psychiatrist, or even a gymnast [you have to be able to keep up] but the most important hat is that of a parent.

In the beginning it's as if you are out there all alone, trying to do this impossible task of raising a special child when there seems to be no others in your situation. I would ask myself, "Where can I go where there are there others who know what I am going through?" I live in Los Angeles, California, in the part of town called South Central. When I found out that Victor had a disability, I tried to find a parent *support group. I knew in my heart there had to be one out there somewhere. Lo* and behold, one day William Deshay, a Service Coordinator from the South Central Regional Center informed me that there was a parent support group located in South Central called Loving Your Disabled Child [LYDC]. He told me to ask for Monica Pope. When I called, it was as if a weight was lifted off of my soul. I could not believe, after feeling alone for so long, that there were other families of color out there with children with disabilities. At this time, my son was nine years old. No one should have to wait nine years to find anything. I had almost given up hope, and for a single parent, HOPE is sometimes all you have. Being forced to give up on all you have is heartless. I was so excited and also afraid at the same time. LYDC gave me hope, faith, empowerment, strength and a sense of belonging. When you are a single parent with a child with a disability, you feel you have to be strong, and no one should see you cry, or see that you hurt inside for your child. You can't have a weakness, show guilt in any way, or society reacts with pity for you and your child. But in all actuality, there is nothing to feel guilty or ashamed of, nevertheless, the feeling is there. There are many nights I sit and stare out the window and say "God, why me, this is hard. I am tired." But somehow the strength to carry on comes out of nowhere. I thank God for parent support groups like LYDC.

This year nearly 100,000 women will become mothers of a child with a disability. Could you conceive of 100,000 parents feeling as if there was no way to handle the job put in front of them. Raising a child with a disability is a job, and I have 11 years experience at this position. I have had to work hard at fighting for my son's rights—harder than being in a boxing ring with Mike Tyson. Tyson could not have hit me harder than getting hit with the fact that my son was not going to progress normally. How was Victor going to get the kind of education he needed? My son has never called me Momma, yet I have hope, I just don't have the skills to teach him to say Momma. I had no idea I could give my input as to my son's education until the parent support group [LYDC] gave a workshop on Individuals with Disabilities Education Act [IDEA] and the Individual Education Plan [IEP]. After the workshop, I wondered if Victor's education plan was really individualized. I thought back to his last IEP meeting. Is Vic getting an individualized education? Let me see, in his last IEP I was told they don't have a speech therapist who could work with him, or a behavioral therapist, and there was nowhere else he could be placed in the school system that could provide for his needs. You tell me, is he receiving an individualized education? Lo and behold, soon after I completed the LYDC workshop, I was able to use that knowledge I had gained. I was able to prevent my son from being expelled due to behaviors associated with his disability and get him a special personal aide. This was my first time playing a major part in my son's education. I am looking forward to my next part.

I am also a college graduate with a BA in accounting, but yet I don't know how to teach my son how to function in society. It's not for the lack of scholastic education; I have that, but what I don't have is training on how to teach my son with a learning disability. At the present time, there are no classes, programs, or training centers in my community offering training to parents with children with disabilities. I think training to empower parents with the knowledge it takes to teach their special children should be the first step. If you have a typical child that is behind in math, English or history, you could buy the books and tutor him or her at home. But who tutors the child with the disability?

I don't think there will ever be one solid answer, but if we work together to empower each other. I mean, the professionals and the parents, no one would feel as hopeless or helpless as we do now.

I truly think when Victor started crying uncontrollably, in his own special way he was asking me, "Mommy, what do I do?"

Chairman OWENS. Thank you. Ms. Retos.

Ms. RETOS. Mr. Chairman and Mr. Ballenger, thank you for the opportunity to come before you today with information concerning the education of my children under the auspices of IDEA.

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Living the course of a child's education is one thing and reviewing it is quite another. Due to this invitation, I reviewed the volumes of forms and papers and reports that I have accumulated over the past 12 years, all of which indicates to me that we have the correct "idea"; we just haven't quite gotten it right yet.

Let me begin by introducing to you, my eldest son. His name is Josh and he is 17 years old. After spending two years in first grade and a half a year in second grade, the school system finally agreed—due to the severe discrepancies that were appearing in his test scores, along with the insistence of his teachers and myself and the inconsistencies in performance in class—that he did indeed have a learning disability.

Their reason for postponement in identifying him, they said, was that his inconsistencies were so widespread and covered so many disciplines, that in the beginning they believed it was just a lack of maturity. So being two and a half years behind, we began the long journey to recovery.

Tests and psychologists and reading specialists and social workers, all became a part of our lives. In the beginning I felt that they were way over my head; I was incredibly intimidated.

I must say, though, that never throughout the course of my children's elementary or middle school experience was there ever an indication that my children's problems were due to their upbringing or to their home life.

I truly believed that there was never a question of the validity of their diagnosis and that the learning disabilities were truly obstacles to the quality of their life.

By the time Josh was in the third grade, he was experiencing severe attention problems, along with hyperactivity. ADHD, Attention Deficit Hyperactivity Disorder, was beginning to affect his learning process.

Although there were signs of this problem early on, it became more serious in the fourth and fifth grade. Although there was no belligerence in his behavior, he did not attend to his school work, lost concentration almost immediately, and was distracted by the slightest noise or movement.

It is my opinion that this disorder is the most serious of all of the manifestations of Josh's learning disability. It is the single most common complaint that comes home from school to this day. "He is not interested," "He doesn't act like someone who wants to learn," "He needs to pay more attention," and on and on.

Alternative teaching methods have proven to be the answer academically, but the lack of concentration, distractibility, and hyperactivity must be addressed in other ways.

These behavioral differences became obvious at home. Although it did not impact on his home life as severely as in school, socially he would be the one to bump the table, spill the drink, et cetera. This is referred to as impulsivity.

His actions were noticed by his friends. At first he was unaware of his friends' negative reaction to his behavior, but as he became an adolescent, there was a dramatic change. He became very aware of the differences in the way he acted or reacted, as the case may be. He became very controlled and rarely lost his temper, and if he did he took control of it immediately.

This is a wonderful example of behavior modification; however, it was effective only for the physical and emotional ends of his problem. The distractibility, inability to attend, are still prominent, coupled with frustration of constant academic failure.

The elementary and middle school professionals had an adequate understanding of this problem. Although the regular education teachers did not have the clear understanding of the problem, the special education support that he received kept moving him along at a pace that was slow. But at least it was forward progress.

All of his testing showed that he had very poor written language skills, poor spelling skills, and very poor math skills. Yet at the same time, his verbal abilities at times, scored off the grading scale.

At one point in middle school, verbal and auditory learning skills were so strong that he tested at the twelfth grade, eighth month level. His general knowledge scores are always far above his grade level. This shows that he is learning, but the test scores, both standardized and comprehensive, always reflect the weakness mentioned above.

When Josh left middle school, he was on grade level in all subjects, including math. He was working well under the special education program. By the time he was in high school, for one year he had lost, according to standardized testing, two grade levels in math.

The freshman year in high school was like taking three giant steps backwards. He was placed in what is referred to as Study Skills. The concept was to give support and reinforcement in areas where there were weaknesses. Any assignments and projects could be guided by a teacher who was certified in learning disabilities. This concept worked well in middle school, but in high school it was a disaster.

Since his freshman year he has fallen another two semesters behind in math and is testing at a third grade level. Spelling is at seventh grade level and verbal skills, as well as general knowledge, tests beyond high school level, which is as high as the test scores go.

Fortunately, his academic frustrations have not spilled over into the rest of his life. Josh is active in our church and has a true sense of social ministry. He works at the Backdoor Ministry as a part-time job and feeds 150 homeless people every day. During the holidays, he delivers food baskets for our Social Action Center, and he is the youth representative to the League of Downtown Churches.

He is a varsity athlete and letters in baseball and wrestling. He's a two-time Peninsula District Wrestling Champion and is named to the Daily Press All Star District Wrestling Team. This is a child who can't do a common math problem and has a difficult time reading. In addition, he will be honored in the Peninsula Sports Club for his achievement in athletics.

It is my feeling that Josh's ability to stay on grade level in elementary and middle school, and his success outside of school, represents a good foundation, both at home and in early education. But the lack of structure in the secondary level has made it next

to impossible for this child to be accepted, let alone keep up in any postsecondary level.

Now I have a second child, and this child does not have the attention problem or the hyperactivity problem that Josh has. Although Jacob does not have as high an IQ as Josh, his disabilities are severe but not as broad. He has no short-term memory, and he has some visual field problems.

When he entered middle school, the learning disabilities team leader recognized his problem immediately. She changed his entire reading program. Within two years he was on grade level. She supported him in his math and spelling, and he was fortunate enough to become involved in an innovative and creative course that improved his grammar and English, as well as his spelling.

He passed the Literacy Passport test on his second attempt. In this school he received the first "A" that he has ever earned, and on the last progress report he has received honor roll grades.

I believe that Jacob is a perfect example of what special education means. A product of the true least restrictive environment, his schedule has been structured around his needs. He has been afforded the opportunity to participate in innovative teaching methods, as well as creative curriculum.

Jacob has a flair for creative writing, and that course, while being interesting to him as well as energizing him, reinforces his spelling and grammar skills, as well as provides him an opportunity to be successful.

There are other components to this success thus far. He is in what Hampton calls a Fundamental School. This is, in essence, a school of choice. Parents are responsible for transportation and a contract is signed that both student and parent are willing to abide by all structures of the school.

Jacob responds well to structure and consistency. His LD teacher and his guidance counselor have a keen understanding of his disability and his weaknesses as well as his strengths. A serious attempt is made to meet his needs, and it has been taken by his counselor so that all regular education teachers have a knowledge and a sensitivity to his special needs.

Watching one's son regress as he did in high school is difficult enough, but sending a second child into the same environment, knowing that there is nothing that resembles individualized education, is a frightening thought.

I believe in the intent of the law. I believe, and I have living proof, that when done correctly it does work. We have just not expanded it to the high school level. We have not even scratched the surface of what was intended by the mandate of transition. We have come so very far, but we have so very far to go.

Thank you, sir.

[The prepared statement of Sharon S. Retos follows:]

STATEMENT OF SHARON S. RETOS, HAMPTON, VIRGINIA

Thank you for the opportunity to come before you today with information concerning the education of my children under the auspices of IDEA.

Living the course of a child's education is one thing, and reviewing it is quite another. Due to this invitation, I have reviewed the volumes of forms and papers and reports that I have accumulated over the past 12 years, all of which indicates to me that we have the correct "idea" but we just haven't gotten it quite right yet.

Let me begin by introducing to you, my eldest son. His name is Josh and he is 17 years old. After spending two years in first grade and half a year in second grade, the school system finally agreed that, due to the severe discrepancies that were appearing in his test scores, along with the insistence of his teachers and myself of his inconsistencies in performance in class; that he did, indeed have a learning disability. Their reason for postponement in identifying him, they said, was that the inconsistencies were so widespread and covered so many disciplines, that in the beginning they believed it was a lack of maturity.

So, being 2½ years behind, we began the long journey to recovery.

Tests and psychologists and reading specialists and social workers, all became a part of our lives. In the beginning I felt that they were over my head. I must say that never throughout the course of my children's elementary or middle school experience was there ever an indication that my children's problems were due to their upbringing or their home life. I truly believe that there was never a question of the validity of their diagnosis and that Learning Disabilities were truly the obstacle to the quality of their life.

By the time Josh was in third grade, he was experiencing severe attention problems, along with hyperactivity. ADHD [Attention Defect Hyperactivity Disorder], was beginning to affect the learning process. Although there were signs of this problem early on, it became more serious in the fourth and fifth grade. Although there was no belligerence in his behavior, he did not attend to his school work, lost concentration almost immediately, and was distracted at the slightest noise or movement.

It is my opinion that this disorder is the most serious of all the manifestations of Josh's learning disability.

It is the single most common complaint that comes home to this day. "He is not interested," "He does not act like someone who wants to learn." "Josh needs to pay more attention," and on and on.

Alternative teaching methods have proven to be the answer academically, but the lack of concentration, distractibility, and hyperactivity must be addressed in other ways.

These behavioral differences became obvious at home. Although it did not impact on his home life as severely as at school, socially, he would be the one to bump the table, or spill the drink, et cetera. This is referred to as impulsivity. These actions were noticed by his friends. At first he was unaware of his friends' negative reaction to his behavior, but as he became an adolescent, there was a dramatic change. He became very aware of the differences in the way he acted or reacted, as the case may be. He became very controlled and rarely lost his temper, and if he did, took control of it immediately. This was a wonderful example of behavior modification, however, it was effective only for the physical and emotional ends of the problem. The distractibility and the inability to attend are still prominent, coupled with the frustration of constant academic failure.

The elementary and middle school professionals had an adequate understanding of this problem. Although the regular education teachers did not have the clear understanding of the problem, the special education support that he received kept moving him along at a pace that was slow. But at least had forward progress. All of his testing showed that he had very poor written language skills, poor spelling skills, and very poor math skills. Yet at the same time, his verbal abilities were, at times, off the grading scale.

At one point in middle school, verbal and auditory learning skills were so strong that he tested at the twelfth grade, eighth month level.

His general knowledge scores are always far above his grade level. This shows that he is learning. But his test scores, both standardized and comprehensive, always reflect the weakness mentioned above. When Josh left middle school, he was on grade level in all subjects, including math. By the time he was in high school for one year, he had lost [according to standardized testing], two grade levels in math.

The freshman year in high school was like taking three giant steps backwards. He was placed in what was referred to as Study Skills. The concept was to give support and reinforcement in areas where there was weaknesses, any assignments and projects could be guided by a teacher who was certified in learning disabilities.

This concept worked well in middle school. In high school it was a disaster.

Since his freshman year he has fallen another two semesters behind in math and is testing at a third grade level. Spelling is at seventh grade and verbal skills, as well as general knowledge, tests beyond high school level, which is as high as the test scores go.

Fortunately, his academic frustrations have not spilled over into the rest of his life. Josh is active in our church and has a true sense of social ministry. We are

members of St. Vincent's Catholic Church in Neweport News, Va. where Josh has worked at the Backdoor Ministry which feeds 150 homeless persons every day. He has delivered food baskets from the Social Action Center, and has been the youth representative to the League of Downtown Churches and to the Parish Council.

He is a varsity athlete with letters in baseball and wrestling. He is the two-time Peninsula District Wrestling Champion, and was named to the Daily Press to the All Star District Wrestling Team. In addition, he will be honored next week by the Peninsula Sports Club for his achievements in athletics.

It is my feeling that Josh's ability to stay on grade level in elementary and middle schools, and his successes outside of school, represent a good foundation, both at home and in the early years of school. But the lack of structure on the secondary level has made it next to impossible for this child to be accepted, let alone keep up on any postsecondary level.

And now I have a second child. This child does not have the attention problems or the hyperactivity problems that Josh has.

Although Jacob does not have as high an IQ as Josh, his disabilities are severe but not as broad. He has no short-term memory, and he has some visual field problems. When he entered middle school, the learning disabilities team leader recognized his problem, and changed his entire reading program. Within two years he was on grade level. She supported him in his math and spelling. He was fortunate enough to become involved in an innovative and creative writing course that improved his grammar and English, as well as his spelling. He passed the Literacy Passport test on his second attempt. In this school he received the first "A" he had ever earned, and on his last progress report he received honor roll grades.

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There are other components to his success thus far. He is in what Hampton calls a Fundamental School. This is, in essence, a school of choice. Parents are responsible for transportation and a contract is signed that both student and parent are willing to abide by the structure of the school and its rules. Jacob responds well to structure and consistency. His LD teacher and his guidance counselor have a keen understanding of his disability and his weaknesses as well as his strengths. A serious attempt to meet his needs has been taken by the counselor so that all regular education teachers have knowledge and sensitivity to his special needs.

Watching one's son regress as he did in high school is difficult enough. But sending the second child into the same environment, knowing that there is nothing that resembles Individualized Education, is a frightening thought.

I believe in the intent of the law. I have living proof that when done correctly it works. But we have just not expanded it to the high school level.

We have not scratched the surface of what was intended by the mandate of Transition.

We have come so very far, but we still have so very far to go.

Chairman OWENS. Thank you. Ms. Berg.

Ms. BERG. Good morning, Mr. Chairman, Mr. Ballenger, and members of the subcommittee. My name is Clara Berg. I am from New York. I'm married to Jake, and we have three beautiful children, ages 12, 13, and 14. Our 13-year-old son, Kenny, was born very premature, and due to a lack of oxygen he became deaf and blind. We were advised that he might not survive his second birthday.

Kenny spent eight months in the hospital, and when we finally brought him home, nobody had given us an idea of what kind of services were available for a child like him. We had to do all the legwork by ourselves; we had to get the therapists services; and most important, we had to try to find the strength to keep our family together.

Kenny survived his second birthday, learned how to sit independently, and also learned how to hit his head against the floor. He did become self-abusive.

We were fortunate that we were able to register Kenny in a preschool program. There we met professionals that sat with us and explained all the very special needs that he had due to his deaf-blindness.

When the time came when I had to go to my first IEP meeting and choose the program that I wanted for him, I was really terrified. Not only because English is not my native language, but because I did not comprehend the terminology that they were using.

The end result: I was afraid to open my mouth and afraid that they were going to send me home without allowing my son to attend any special program. A guardian angel came in the shape of the advocate of the preschool program that we were attending at the time. She taught me how to ask for services and how to fight to get them.

Now, I am not such a great fighter, so I decided instead of fighting the system, let me work with my District, and that's what I did. I became a volunteer and I was translating for Spanish-speaking families in the District, and that way I got to see what services were being offered and how they were rendered.

Kenny entered and exited many programs in a short period because they could not deal with his deaf-blindness and his self-abusive behavior. We were sure that his behaviors were his attempts to communicate his needs and desires to the outside world.

We did all the research, but there was no program available near our home that could offer total communication on a one-to-one basis, twenty-four hours a day, and that's what he needed.

Even though we were not ready, we decided to look for a residential setting that focused on total communication and sign language. We were not able to find that program in New York, and therefore we decided to go to Massachusetts. Kenny is now at Perkins School for the Blind in Watertown.

Life started changing for Kenny and our family at the time. Kenny went through a slow process of learning how to use signs to ask for such things as food, drink, sleep, to go to the bathroom, play, mommy, water, and our family went through the process of learning how to cope with separation.

Seven years have gone by, and although I love Perkins, and it has been a second home for me and my family, I dream of the day I will be able to bring Kenny home—or closer to home.

I realize that children who are deaf-blind make up a relatively small group in the world of persons with disabilities; however, what makes Kenny's world very different is the uniqueness of the combination of a lack of vision and hearing, which affects all aspects of his life.

It affects the ability of Kenny to interact with other children and adults because he cannot communicate with them. It affects how to learn and to take care of himself. Kenny doesn't know how to eat independently actually, or to dress independently or to take care of himself. It also affects the way he learns different skills in school and to find eventually, when he grows up, a meaningful employment.

We need more training of professionals in the field and more support for the agencies and schools serving children who are deaf-blind. We need to help the families to cope with their fears and frustrations. We need to enforce the laws that are designed to help our children to have a successful transition when they become adults after age 21.

I hope Federal funds will continue to support programs like the State and Multi-State Deaf-Blind Projects, TRACES, and The Helen Keller National Center, that provide training for teachers and families, as well as the research and demonstration projects that have given us the methodologies and practice that we need to teach our children who are deaf-blind.

It is through the application of valuable Federal funds that children and young adults who are deaf-blind will lead quality lives characterized by independence, productivity, and inclusion in their community.

I really have to thank you for the opportunity to be here today.

[The prepared statement of Clara Berg follows:]

STATEMENT OF CLARA BERG, BAYSIDE, NEW YORK

My name is Clara Berg. I'm married to Jake, and we have three children, ages 12, 13, and 14. Our 13-year-old son was born 3½ months premature, and due to a lack of oxygen he became both deaf and blind. We were advised that he might not survive his second birthday.

Kenny spent eight months in the hospital, and when we finally brought him home, nobody had given us an idea of what kind of services were available for a child like him. We had to do all the legwork ourselves: getting therapists, services, and most important, trying to find the strength to keep our family together.

Kenny survived his second birthday, learned how to sit independently, and how to stimulate himself by hitting his head against the floor.

We were fortunate and able to register Kenny in a preschool program. There, we met professionals that sat with us and explained all the very special needs that he had due to his deaf-blindness.

When the time came where I had to go to my first IEP meeting and choose the program I wanted for him ... I was terrified! Not only because English is not my native language, but because I did not comprehend the terminology that they were using. The end result ... I was afraid to open my mouth and afraid that they were going to send me home without allowing my son to attend a special program.

A guardian angel came in the shape of the advocate of the preschool program. She taught me how to ask for services and how to fight to get them! I am not such a good fighter, so I decided to join my District and learn more about how services are offered and rendered.

Kenny entered and exited many programs in a short period because they could not deal with his deaf-blindness and his self-abusive behavior.

We were *sure* that his behaviors were his attempt to communicate his needs and desires to the outside world.

We did all the research, but there was no program available near our home that could offer total communication on a one-to-one basis, twenty-four hours a day.

Even though we were not ready, we decided to look for a residential setting that focused on total communication. We were not able to find that program in New York, therefore, we decided to send him to Massachusetts, to Perkins School for the Blind.

Life started changing for Kenny and our family. Kenny went through a slow process of learning how to use signs to ask for such things as: food, drink, sleep, bathroom, play, mommy, water ... and the family went through the process of learning how to cope with separation.

Seven years have gone by, and although I love Perkins, and it has been a second home for me and my family, I dream of the day I will be able to bring Kenny closer to home.

I realize that children who are deaf-blind make up a relatively small group in the world of persons with disabilities. However, what makes Kenny's world very different is the uniqueness of the combination of lack of vision and hearing which affects all aspects of his life, such as his ability to interact with other children and

adults, to learn how to care of himself, to learn different skills in school and to find meaningful employment when he grows up.

We need more training of professionals in the field and more support for the agencies and schools serving children who are deaf-blind.

We need to help the families to cope with their fears and frustrations.

We need to enforce the laws that are designed to help our children to have a successful transition when they become adults after age 21.

I hope Federal funds will continue to support programs like the State and Multi-State Deaf-Blind Projects, TRACES, The Helen Keller National Center, that provide training for teachers and families, as well as the research and demonstration projects that have given us the methodologies and practices that we need to teach our deaf-blind children.

It is through the application of valuable Federal funds that children and young adults who are deaf-blind will lead quality lives characterized by independence, productivity, and inclusion in their communities and families.

Chairman OWENS. Thank you. I think that each one of your individual experiences adds very valuable information to our record, in terms of what is going on, and it puts a human face on this whole process of searching for the best way to improve the legislation.

I have a few questions. Ms. Woods and Ms. Loewe, you both are from Los Angeles. Have you learned about the LYDC, Love Your Disabled Child program, Ms. Loewe?

Ms. LOEWE. Yes, I have. I also attend a parent support group there, and that was the first support group I have ever attended. I have been going there for the past six months.

Chairman OWENS. You live in the same part of Los Angeles?

Ms. LOEWE. That's correct.

Chairman OWENS. You do?

Ms. LOEWE. Yes, we live in the same part.

Chairman OWENS. Is there one group for the whole city?

Ms. LOEWE. That's the only one that I have found in Los Angeles, actually in Los Angeles or Los Angeles County. As you know, Los Angeles is very large.

Chairman OWENS. Would you say—mark as number one priority, the provision of such groups—if there's any one thing you had to have, it was that?

Ms. LOEWE. If there was any one thing that they can do for parents with children with disabilities, it would be to fund more projects like LYDC. They have helped me in actually the day-to-day living.

I was laid off from my job not too long ago, which was a prominent law firm, and when I applied for aid, the person came to my house and said that I wasn't eligible. It was a program called IHSS, which is In Home Support Services.

I don't know if they have that out here, but the person said that I wasn't eligible—because I was a parent of a handicapped—to get paid to stay home and take care of my son. What I did was call Monica Pope, at home, and she talked to the guy for about 10 minutes. By the time she finished, the guy was saying, "Okay. We'll try to get you an amount—the maximum amount of hours."

Me, as a parent——

Chairman OWENS. Let me let you finish when I return. There's an emergency that I have to attend to. I was trying to finish questioning the panel. Can we recess for about 10 minutes? Stay where you are; we'll continue the question.

[Recess.]

Chairman OWENS. Do you want to ask your questions?

Mr. BALLENGER. Yes. You communicate very well in this committee, and I would—I was fascinated to find out that the thing is completely educational. I have been lucky in my life that all of my children were healthy and had no d'sabilities, and my grandchildren are the same way.

I wondered if it's possible, having been a county commissioner once upon a time, and we spent over and over and over again, just a monstrous amount of money and time to try to prevent premature births. I know in your specific case that was the cause.

Prenatal care is one thing that I have always felt over and over again that we don't put enough money into. I know it would have probably helped you, but would it have assisted the rest of you if there had been educational programs on prenatal care?

Ms. WOODS. Actually, I did go through prenatal care. My son was actually premature, but he was handicapped through his dad; the use of cocaine affected the fetus. I did not use any drugs, but through his father he contracted cerebral palsy.

Mr. BALLENGER. Yes, ma'am.

Ms. LOEWE. I personally received prenatal care for both of my children, so I don't see how that could have really adjusted anything; however, in our community, I think there is a need for more information about prenatal care.

Mr. BALLENGER. Right. Well, how did your organization, LYDC, get its funding? Did Mrs. Pope start LYDC?

Ms. WOODS. The director of it, which is Monica Pope, and another, the pastor of her church—it's actually a Christian group, and it's held at the church. She has two children who are disabled with spina bifida, and actually her children have multiple disabilities.

With her having the two children with disabilities, along with the pastor of the church who has a child with disabilities, they started the program. The program has actually been in effect about four to five years, somewhere around there, but we have been working with no funding.

It's just from parents, you know, having a little extra money or donating their services and things of that nature. They have put me on as part of the staff, and so I kind of help out where I can and that helps the funding because we kind of group together.

Mr. BALLENGER. Right.

Ms. WOODS. The group does not have enough money to reach a lot of parents. There are a lot of parents in the community that don't know about LYDC because they just don't have the funds to reach out to the other parents.

We have started to make videos and things of that nature, to do outreach. The other day we ran out of videotapes, so somebody had to go in their pocket to buy a videotape.

It might not sound like much, the price of a videotape, but if you think you want a lot of videotapes to send to the different schools or just to have advocacy groups, that is a lot of money.

Mr. BALLENGER. IDEA doesn't provide money for that sort of situation?

Ms. WOODS. I think they do get a small grant from IDEA, but what they got was, I think——

Ms. SPINKSTON. It's part of the experimental project.

Ms. WOODS. Right. I think they got, like, $10,000, $20,000 for the year.

Mr. BALLENGER. They did? You know, it took forever to get started on this.

Ms. WOODS. Not that much?

Mr. BALLENGER. Not that much.

Ms. WOODS. No, $5,000?

Mr. BALLENGER. No, our budget was $50,000.

Ms. SPINKSTON. Yes, something like that.

Ms. WOODS. Five thousand dollars for the year.

Mr. BALLENGER. Okay. Sometimes we don't spend money wisely, but I don't think with a $150,000 budget she could have spent that.

Ms. WOODS. I really didn't know. I'm putting an imaginary out there. Actually, that sounds worse, $5,000.

Mr. BALLENGER. Ms. Retos?

Ms. RETOS. Yes, sir?

Mr. BALLENGER. Is there a special program in Hampton?

Ms. RETOS. I'm in Hampton, sir. Yes, sir.

Mr. BALLENGER. Is there an organization like the one out there in Los Angeles?

Ms. RETOS. I'm not aware of anything like that. The information that I have given you, and my experience, has all been done through the school system. There are many support groups for different types of disabilities, but my experience is only with learning disabilities.

I have worked as an advocate since my child has been identified through the Learning Disabilities Association, but I also do other services. I have worked with Lieutenant Governor Beyer of Virginia on some programs that he had for coordination of services for persons with disabilities, and I also serve on the Special Education Advisory Board of the school system that the children go to in Hampton.

All of the experience that I have stated in my testimony is done through the actual Special Education Department of the school system in Hampton.

Mr. BALLENGER. You say that basically it falls apart once you leave grammar school?

Ms. RETOS. Absolutely; it falls apart once you get into high school and, of course, I don't think that we have yet begun to work seriously on what is meant by true transition.

The latest testimony here is certainly touching and it is just wonderful, but I wonder, really, where we are as these children become adults. What are we going to do to make these children adults who can function and work?

I really believe that the intent of the law was to move them into adulthood to where they can function and work, and we just haven't even done it for children who are able to have the grounding they might have had. Even at that level of disability there is little out there for people with disabilities as they become adults.

The programs are scattered and they're wonderful if you can find one, but to have any consistency or any network through these programs—I have not seen that happen and it's unfortunate.

Vocational rehabilitation is something that is wonderful, but it's my understanding, from hearing talks on the Federal level, that vo-

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cational rehabilitation has a tendency to sort of be a regional type of a thing where they work in some level wherever you are. Say, in Hampton they happen to concentrate on persons who are hearing impaired or whatever.

There's really no consistency in the type of services that they can give for all sorts of disabilities. It happens to be localized on how these people work comfortably or where their comfort zone is, and that's kind of hard to deal with.

Maybe I have a child who has a disability, a learning disability, and perhaps receiving some help in a community college level would be something that vocational rehabilitation might be able to help them with.

They may say, "I'm sorry, but we don't have enough money to help your child because he isn't disabled enough. We work with these types of disabilities, or we're very strong in these types of disabilities." So it makes it real difficult. I haven't seen a lot of consistency when it comes to that.

Mr. BALLENGER. Is that a statewide program that you're speaking of, at the Federal level?

Ms. RETOS. Yes. Well, it's a Federal program, but it goes——

Mr. BALLENGER. Yes, ma'am, but what you're specifically talking about is a statewide program in the State of Virginia.

Ms. RETOS. Yes.

Mr. BALLENGER. Now, quite often we don't recognize how fortunate we are—those who have been fortunate enough to have nondisabled children.

You got any questions of me? I'm not real knowledgeable of this program, but, as I said in my opening statement, we recognize that once you start with these things, then you really see how short the funding is. Yes, ma'am?

Ms. WOODS. If anything is implemented, how long will it take?

Mr. BALLENGER. Well, the sad part about it is—I think Major said it when we talked about cutting back your program—and I asked, "Did we do that?" and he said, "No, we didn't do it."

Congress is divided into two groups. We are what you call an authorizing committee. We come up with the programs, we come up with the ideas, and we suggest how much money should go into a particular program.

Then it leaves our hands and it goes to what they call the Appropriations Committee, and the numbers come out different. They make the decision about the money and how much will be divided up amongst the various and sundry programs.

We just did a budget, and the budget doesn't really mean anything because we change that every day. There are 13 appropriations bills, and I would think yours is probably in the education department.

So you would look at our education appropriations bill, and look in there and find out your number. Our year starts October the first and that would be the time that you could look for any financial changes, I would think.

Every once in a while we pass what they call an emergency bill for, you know, the earthquake you all had out there, and you still don't have anything going for you.

In October the money starts flowing for next year, and so we'll spend the time between now and next October deciding how much money to put there, where it goes, and whether health care gets it or education gets it. Watch us on C-Span and you'll find out.

I'm glad that you all were able to come and I'm sorry that Major had a problem.

[Recess.]

Mr. BALLENGER. Why don't we ask you ladies to step back—we have another panel—and the Chairman will be here—well, here he is now, the boss.

Chairman OWENS. My apologies.

Mr. BALLENGER. Oh, no problem. We were having an educational meeting for me.

Chairman OWENS. The question I was going to ask all of you was about the parents getting reimbursed for providing services, and you started to talk about that, I think, just before I left. You discovered that you could get paid?

Ms. WOODS. Well, yes. I discovered that I was eligible, because my son was handicapped, for getting funds for taking care of him instead of someone else doing it for me. Monica Pope was the one that actually got me the funds from her home, over the telephone. Had it not been for her, it would have taken me a couple of months because I would have had to appeal it and go before a judge.

Ms. LOEWE. I would like to mention something about that. It was at an in-service at LYDC that I heard about In Home Support Services. I was receiving it, but I did not know that I could be my own child's provider.

I'm a wonderful parent who fought the State of California and won that; I did this in-service, and it was right after that that I went and called this agency and attempted to put it in my name.

I did that six months ago. I just received the form this past week, and the form is confusing because it says that the person who wants to be the service provider cannot be the guardian, even though that is your legal right. So I think it confuses many parents and they think, "Oh, well, I can't be the provider so I need to put it in someone else's name."

Then when you call—it's terrible when you call. They act like they have never heard of you before. I called every month, and each time I called they acted like they have never heard of me. They will give you misinformation and tell you that you cannot be your child's provider, even though you do have that right.

Chairman OWENS. Were you able to appeal to the Department of Education to deal with that kind of treatment?

Ms. LOEWE. No, I have not done that. I was waiting on this form; now that they finally sent it to me, I really don't know what I should do next. I know that I'm just going to fill it out, and if they reject it, then go from there.

Chairman OWENS. Ms. Woods, have you ever asked the school to provide your child with speech therapy?

Ms. WOODS. Yes, I did. I asked them for speech therapy, a behavioral therapist, and—oh, what was it?

Chairman OWENS. They said that they could not? It was not available?

Ms. WOODS. They said that there was not one available for a child of Victor's needs. Because he has cerebral palsy and autism, it puts him in a special learning category at that school. Actually, in his classroom, he's smart but not smart enough. He's not smart enough to be moved to the next level, so he kind of stays stagnant right there in that position.

Chairman OWENS. Ms. Retos, for you, special education has worked part of the time for one child, and you're afraid that you're going to have the same problem with the second child.

Ms. RETOS. Afraid it will come to an end when he gets into high school, sir.

Chairman OWENS. Have you attempted to use any advocacy assistance to prepare the situation in high school for your second child or the——

Ms. RETOS. Well, I have a lot of advocacy experience on my own, and I know what the high school has to offer. When you have a child who is functioning on a level that is passable, it is unlikely——

I mean, I have stories of IEPs that I have refused to sign. When you do an IEP, they state where you will be within the time of the next IEP. He has never ever reached his goal in that area.

I have had him moved every time there's been a special education teacher available in whatever course he needs to take that year, whether it be freshman, sophomore, or junior year. I have always seen that he is placed in that teacher's class, but it's a constant battle to advocate for him, and those teachers are available on a sporadic basis.

One year they did have a special education health teacher so he took her course; one year they had a special education math teacher who taught pre-algebra so he was assigned to her class.

We have what they call a study skills class, and the child is supposed to be in a position to go into that class. She's supposed to reinforce where his weaknesses are, and then she's supposed to be in a position to still give him some sort of support.

I found a hall pass in his pocket one time when I was doing the laundry, and it was a hall pass for one week to go to the library. I asked him, "What are you doing going to the library every week during your study skills class?" and he said, "I can't stand it in there. It's too noisy, and all the teacher does is scream at all these—the L.D. kids that are in there."

So I found out that it was that. It was a cross-categorical group of people. They were throwing papers back and forth and doing whatever high schoolers do when they are bored, and he said, "I would just as soon go to the library and read Sports Illustrated." I can tell you, he's not going to read a history book in the library. So then I had to have him taken out of that class and moved on.

I mean, the horror stories are—it's so close to working but it just doesn't quite work. If there's just a little more effort put into it, a little more consistency, making sure that there's availability of these teachers to help these children, and that they're doing what they're supposed to do and that the law intended for them to do, many, many of these students could be working at above average or average levels anyway.

They need to get into a program of some sort that can teach them to do a job and move them on to being functional and successful taxpaying citizens. Instead, we have children who may be on grade level, or maybe above, who absolutely fail when they get into high school, and, worst of all, of course, the transition end of things. When they get into college, they're just not at all fit for that, no matter how they get into school.

Chairman OWENS. So what you're saying, that in the earlier grades and middle level, there wasn't availability of appropriately trained and certified teachers?

Ms. RETOS. Yes. I had success in both middle schools. The second child went to a middle school that was a fundamental school, very structured and very strict.

The first child went to one that was not, but he still had special education programs there and he happened to be fortunate enough to come across some regular education teachers who gave him a little latitude because of the fact that he has this hyperactivity. He didn't have to be a square peg in a square hole.

I mean, he could move around a little. If he forgot his pencil, she had a box of pencils; it just didn't bother her. He worked well in that environment, and the younger son worked well in the more restricted environment.

When the first child got into high school, it just fell apart, and I'm afraid that the same thing's going to happen to the youngest child.

Again, he has been performing a whole lot higher if he's in an honor role situation, but he hasn't had a consistency of failure and therefore he is in a position to do better in school because he's not frustrated by constant failure.

Chairman OWENS. Is all this left up to accident? You were accidentally fortunate to have a good experience in earlier school, and now the high school situation is such that the school system does not attempt to provide a safe environment and right curriculum, and appropriately trained teachers, and things of this respect——

Ms. RETOS. Yes. I don't know that it's necessarily—pardon me.

Chairman OWENS. They don't try to meet those needs?

Ms. RETOS. I really do believe that once you get into a high school level, they're really not interested in the special education children.

In grade school they have self-contained classes for the more severe, and they feel like they have given them a foundation through that. The whole idea is to mainstream and get them into the mainstream of education.

Now we're talking about total inclusion, and the idea of that is—I can't even imagine how they would deal with total inclusion if they can't even get the children working at a good level in high school, when they have the full continuance of services available to kids when they're in grade school and in middle school.

That still doesn't work in high school. If they start putting cross-categorical problems all into regular education classes, by the time—they'll never get into high school. It's my opinion. Not unless they have a very, very strong continuum of services for the students who are all in regular education classes.

Chairman OWENS. Thank you. Ms. Berg, do you work with other parents who have children in similar situations as yours?

Ms. BERG. Yes, as a matter of fact, when Kenny turned four I was called to the Jewish Guild for the Blind to join four other families, and we started to meet on a—I would say, every other month. That four families turned into 15, and we were the founders of the New York Parent Network, serving children who are deaf-blind. It serves all New York State. The group today has 150 families, and we support each other. It's all through the State. I think we are doing a great job with the children, trying to fight for a better education for them, and with the families giving them support.

Chairman OWENS. You actually helped to start this organization, which is now statewide?

Ms. BERG. I'm the founder and the original president of the organization, yes.

Chairman OWENS. Congratulations.

Ms. BERG. I also have to add that I was very honored last year to become a part of the National Parent Network, which is an organization that centralizes all the State parents' groups that deal with blindness.

The National Parent Network is going to change its name to N-F-A-D-B, National Family Association for the Blind. This is going to be in June and probably here in Washington. That means, I am in touch with families all over the State.

I had a chance to speak to Maria a few minutes before. One of the things that I did mention was that due to the fact that I speak Spanish, it was very helpful for me to really get together with families in the New York area. I would say 50 percent of the group is of Spanish background.

We have a lot of single parents. Many of the cases that I deal with are children who were premature due to the parents' use of drugs. I deal with foster families, and the fact that I am bilingual helped a lot and gives the families who do not have a chance to speak for themselves—it empowers them also to know that there is somebody—many somebodies—helping them.

Chairman OWENS. Well, thank you all. Your testimony will be very useful. If you think of anything else you would like to have added to the record within the next 10 days, please let us know. Thank you for being here.

Ms. WOODS. Thank you.

Ms. BERG. Thank you.

Chairman OWENS. Our third and final panel consists of Mr. Gerald I. Rosenberg, Rockville, Maryland; Ms. Karen Draper, Middletown, Maryland; Ursula Markey, New Orleans, Louisiana; Ms. Jeanne Gerhardt, Hickory, North Carolina.

As you heard me say to the previous panel, we have your written testimony. If you want to follow your written testimony, you may, and, of course, we will elaborate on certain points in the question-and-answer period.

You may begin, Mr. Rosenberg.

STATEMENTS OF GERALD I. ROSENBERG, ROCKVILLE, MARYLAND; KAREN DRAPER, MIDDLETOWN, MARYLAND; URSULA MARKEY, NEW ORLEANS, LOUISIANA; AND JEANNE GERHARDT, HICKORY, NORTH CAROLINA

Mr. ROSENBERG. Thank you very much. Good morning, Chairman Owens, Mr. Ballenger.

My name is Gerald Rosenberg. I would like to thank the subcommittee for inviting me to share my thoughts with you on the vital role that separate special education schools play in our son Danny's education. I would also like to thank the Congress for its continued support for Public Law 94–142, the legislation that brought Danny's school into existence and allows him and many other students at special schools to be appropriately educated.

I would like to tell you a little about our family. I live in Rockville, Maryland, with my wife, Idelle, and our two children, seven-year-old Allison and five-year-old Danny. Danny attends Longview School in Gaithersburg, Maryland, a public school that provides a broad array of intense special education services to severely multiply-handicapped students in Montgomery County.

Danny attends Longview because he has extensive physical and cognitive needs arising from a virus he contracted at birth that led to cerebral palsy. Danny has poor use of his limbs, cannot independently sit, and is unable to speak.

Despite his needs, Danny is bright-eyed and alert. With the gaze of his eyes, his facial expressions, and the cadence of his voice, Danny lets us know, in fact, how much he knows and how much he wants to be like other able-bodied children.

When, through hard work, Danny performs a difficult task, such as pointing to a picture in a book in response to a question, purposefully grasping an object, or standing with assistance, he smiles with pride at his achievement.

Consequently, it has been our family's goal to identify scholastic environments where educational achievement and hard work are stressed and where Danny will be challenged. Therefore, we are committed to the idea that Danny's education must be intensive and focused, and that the hard work of his teachers, his parents, and of Danny himself will provide him with his greatest opportunity to develop the skills necessary for true integration into society.

Even before Danny had reached his first birthday, the Montgomery County Public School System had been following him and providing him with special education. At every juncture when it has become appropriate to consider alternative placements, we carefully weighed the possibilities and reached an informed opinion.

Last year it was time again to review placement issues. We and the school system considered full inclusion, a separate class in a regular school, and a separate school. We collectively decided that the separate school, Longview, was the only appropriate placement for our son.

Given what you have heard, you may be surprised that parents of a special needs student would agree to a separate school placement. While critics of separate schools claim these schools amount to little more than institutional warehouses, I am here to tell you that Longview simply does not fit the stereotype.

You may have heard that parents of students at separate schools are passive and are merely looking for respite care. At Longview there is significant parent involvement at all levels of the school, from the management committee down to the individual classroom.

Parents give, and the school accepts, significant amounts of input. The principal, assistant principal, teachers, and therapists are readily available to discuss issues with parents. In fact, Longview provides us with far more information about Danny's progress than the neighborhood school provides us about our daughter's.

You may also have heard that staff at separate schools are unmotivated and only worry about babysitting the students. In fact, the school strives to have its students achieve meaningful educational goals; it doesn't merely perform custodial functions.

The staff seriously attempts to implement IEPs, internally evaluates the effectiveness of its programs, and demands hard work from the students. Although Danny and his classmates are only five years old, their teacher is already requiring homework.

Critics of special education schools also contend that the staff at separate schools are lethargic and lack creativity. To the contrary, the Longview staff are innovators in special education.

Longview, along with its sister school, Stephen Knolls, are the first locations to introduce the MOVE program to Montgomery County. MOVE is a program entitled Mobility Options Via Education, where with the use of specially designed equipment, severely disabled students otherwise incapable of sitting, grasping, standing, or walking are able to perform these functions and to achieve increasing independence as accompanying supports are removed.

Students participating in the program not only obtain motoric benefits, but enhance their self-esteem from successfully meeting reasonable but demanding goals. MOVE also provides cognitive benefits, as increasing independence gives the students a different perception of their world, one that they are learning to manipulate and navigate.

Because the instructional staff at Longview is learning MOVE just as the students are, the centralization of the program in one building allows for developing MOVE much more quickly than could occur if these classes were dispersed throughout the school system.

For Danny's development, the programming available at Longview is critical. Teachers, aides, and therapists cooperate in ensuring that IEP goals are incorporated into the fabric of the day, thus making the learning of tasks relevant for Danny.

For example, Danny currently is learning how to use a picture board to communicate. The staff expects him to use the board in responding to questions in the classroom, to indicate his food preferences at lunch, and to indicate to the staff when he needs to go to the bathroom.

Likewise, Danny works on his mobility goals in the MOVE program by using his specialized walker, called a gait trainer, to travel between rooms when classes change.

Distractibility is an issue for Danny, and the Longview environment keeps distractions to a minimum. Few bells ring in this school and the hallways are quiet——

[Laughter.]

Mr. ROSENBERG. [continuing] couldn't go to school here—thus facilitating Danny's ability to focus on the task at hand.

Longview is more than merely a centralized location for providing eclectic services to severely disabled children. If the school's only virtue was that it functioned efficiently from an administrative perspective, it would be difficult to justify the school's existence.

The real virtues of Longview, as well as of other special education schools, lie beyond what services are provided and extend to the unique ability of separate schools to provide high quality services for developing skills.

For students like our son, where there are no bright road markers to assist in indicating what teaching methods will work, Longview serves as a laboratory in diagnostic and teaching techniques. The wealth of experience in the staff in educating severely disabled students allows for constant experimentation in what is appropriate educationally for Danny.

This experimentation is further enhanced by the close proximity in which experienced teachers and therapists teach classes. When a teacher has a problem with a particular student, he or she has the ability to conveniently consult with other teachers and therapists who are nearby all the time.

Such collaboration is impossible in a regular school, where a special education class is likely to be isolated and where therapists only appear in the building for the few hours a week in which they may see students.

Thus, we, like other parents of students with disabilities in Montgomery County and across the country, support separate special education schools because we believe they offer high quality education and because they are uniquely appropriate for our children.

While it is our preference to focus on the quality of our son's education, the politics of the day have forced us to focus on the where of it. Two years ago Montgomery County was in danger of losing its separate schools when advocates of inclusion argued that not only was it wrong for any students to be educated in separate programs, but that it was cheaper as well to educate them all in their home schools.

Parents of special needs students in a wide variety of programs representing the full continuum of placements and disabilities, ranging from learning disabilities to mental retardation, in Montgomery County banded together to set the facts straight on the costs of inclusion and opposed implementation of the proposal on the merits.

Fortunately, the school system and the school board used their good common sense to reject such a radical and illegal proposal. We urge you today, for the sake of Danny and his classmates around the country, to use your good common sense and continue to support IDEA's guarantee of a free, appropriate education for these students.

Refrain from tinkering with a law that already seriously addresses special education concerns. You are to be congratulated for crafting a fine law that protects the rights of many families by

mandating that educational quality above any other goals should be the focus of special education. Thank you very much.

[Additional materials submitted by Mr. Rosenberg regarding class action suits in Maryland opposing inclusion are available at the subcommittee office.]

[The prepared statement of Gerald Rosenberg follows:]

STATEMENT OF GERALD I. ROSENBERG, ROCKVILLE, MARYLAND

Good morning, Chairman Owens, Mr. Ballenger and to the rest of the subcommittee attending this hearing. My name is Gerald I. Rosenberg. I would like to thank the subcommittee for inviting me to share my thoughts with you on the vital role that separate special education schools play in our son Danny's education. I would also like to thank the Congress for its continued support for Public Law 94–142, the legislation that brought Danny's school into existence and allows him and many other students at special schools to be appropriately educated.

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Danny attends Longview because he has extensive physical and cognitive needs arising from a virus he contracted at birth that led to cerebral palsy. Danny has poor use of his limbs, cannot independently sit, and is unable to speak. Despite his needs, Danny is bright-eyed and alert. With the gaze of his eyes, his facial expressions, and the cadence of his voice, Danny lets us know, in fact, how much he knows and how much he wants to be like other able-bodied children. When, through hard work, Danny performs a difficult task, such as pointing to a picture in a book in response to a question, purposefully grasping an object, or standing with assistance, he smiles with pride at his achievement. Consequently, it has been our family's goal to identify educational environments where educational achievement and hard work are stressed and where Danny will be challenged. Therefore, we are committed to the idea that Danny's education must be intensive and focused; and that the hard work of his teachers, his parents, and of Danny himself will provide him with his greatest opportunity to develop the skills necessary for true integration into society.

Even before Danny had reached his first birthday, the Montgomery County Public School System had been following him and providing him with special education. At every juncture when it has become appropriate to consider alternative placements, we carefully weighed the possibilities and reached an informed opinion. Last year it was time again to review placement issues. We and the school system considered full inclusion, a separate class in a regular school, and a separate school. We collectively decided that the separate school, Longview, was the only appropriate placement for our son.

The Longview School

Given what you have heard, you may be surprised that parents of a special needs student would agree to a separate school placement. While critics of separate schools claim these schools amount to little more than institutional warehouses, I am here to tell you that Longview simply does not fit the stereotype. You may have heard that parents of students at separate schools are passive and are merely looking for respite care. At Longview there is significant parent involvement at all levels of the school, from the management committee down to the individual classroom. Parents give, and the school accepts, significant amounts of input. The principal, assistant principal, teachers, and therapists are readily available to discuss issues with parents. In fact, Longview provides us with far more information about Danny's progress than the neighborhood school provides us about our daughter's.

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But Longview is more than merely a centralized location for providing eclectic services to severely disabled children. If the school's only virtues were that it functioned efficiently from an administrative perspective, it would be difficult to justify the school's existence. Why not put all of these students in regular schools? The real virtues of Longview, as well as of other special education schools, lies beyond what services are provided and extends to the unique ability of separate schools to provide high quality services for developing skills. For students like our son, where there are no bright road markers to assist in indicating what teaching methods will work, Longview serves as a laboratory in diagnostic and teaching techniques. The wealth of experience in the staff in educating severely disabled students allows for constant experimentation in what is appropriate educationally for Danny. This experimentation is further enhanced by the close proximity in which experienced teachers and therapists teach classes. When a teacher has a problem with a particular student, he/she has the ability to conveniently consult with other teachers and therapists who are nearby all the time. Such collaboration is impossible in a regular school, where a special education class is likely to be isolated and where therapists only appear in the building for the few hours a week in which they may see students.

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Chairman OWENS. Thank you very much. That last bell you heard, was that a quorum call?

Mr. BALLENGER. What three bells? I don't know.

Chairman OWENS. It's a quorum call, if it is.

Mr. BALLENGER. A quorum call.

Chairman OWENS. Would you verify that? I think it's a quorum call. I don't mind missing it, if you don't.

Mr. BALLENGER. I don't either, no.

Chairman OWENS. We'll continue, if it's just a quorum call. Ms. Karen Draper.

Ms. DRAPER. Good morning. My name is Karen Draper. Mr. Chairman and Congressman Ballenger, I want to thank you for allowing me the opportunity to testify before you about the inclusion of children with disabilities.

My husband and I have two wonderful children. They attend their neighborhood school, Myersville Elementary, in Frederick County, Maryland. Our daughter, Samantha, is six and is in the first grade. She is very bright, strong-willed, and funny. She is also very sweet and sensitive to other people's needs. This, I'm sure, is due in part to her brother.

Preston is 10. He is in the fourth grade and has been fully included for three years. He is smart, stubborn, has a temper to match his red hair, and has a wonderful sense of humor. He also has severe spastic quadriplegic cerebral palsy, which means that he is virtually trapped in a body that doesn't work very well. Preston uses a wheelchair.

I'm happy to say I can no longer describe him as completely nonverbal, but he does have a very limited vocabulary right now. He needs a computer to communicate, has a mild seizure disorder, mental retardation, and some visual impairments.

With all this, I am often asked, "Why inclusion?" My answer is always another question, "Why exclusion?" When is it ever right to exclude children from their natural environments, such as their neighborhood schools, age-appropriate friends, community functions, soccer games, birthday parties? The list is endless.

To gain the answer to this question, our family traveled a long journey that eventually led us right back to where we started from, our home, our community. Our journey into inclusion began July 19, 1983, the day Preston was born. Due to the fact that we almost lost him several times after his birth, we were so thankful to finally have Preston with us and healthy.

As happy as we were, I couldn't help but notice the awkward stares, the quick glances away. As Preston grew older and required a wheelchair, it became painfully obvious that society as a whole was uncomfortable by his presence; that they didn't know how to talk to him, or even if they could talk to him.

So the solution was to turn away. At that time, we were still living in the world of exclusion, and I can tell you firsthand it was a very lonely world.

You see, when Preston was born he was not only given a name by his father and me, but he was given a label by society. Because of this label he was put into various categories, categories that were usually about what he couldn't do and what we should never expect him to do because his label of severely and profoundly handicapped said so.

When it was time for Preston to begin his formal education, we were told that he needed to go to a special school for handicapped children, and at that time we did not realize that we even had a choice. This is not a criticism of segregated schools.

I realize that by law there needs to be a continuum of services for parents who choose not to include their children in all aspects of their community, but for us it was one more form of excluding Preston from the natural daily happenings that his younger sister was beginning to experience.

As our daughter entered her preschool, it became clear that our children's worlds were completely different and that neither understood or felt comfortable with the other. We constantly had to explain Preston to everyone because no one had an opportunity to get to know him.

He was always seen as a visitor, not a part of a group. We found ourselves always trying to find ways to fit him in instead of him fitting and growing into the community naturally like his sister. The separateness that segregation brought never felt right.

In reaching our decision to take Preston out of his segregated environment of five nonverbal classmates into a fully inclusive classroom of 23 very verbal classmates, I researched the pros and cons of inclusive education thoroughly, and in doing so we first had to realize what our vision was.

First, what kind of future do we want for Preston, and, second, how do we get there. Our vision was easy to establish. It was built on the fundamental belief that it was Preston's civil right to attend his neighborhood school and should not be a privilege for those considered less than perfect. It was also our belief that limited expectations would further disable an already disabled child.

We wanted Preston to be a part of his community; to have friends that he could interact with at an educational and social level; to be exposed to a wide range of activities, people, environments, and ideas; to become involved in social activities outside of the school; to attend school with his sister; to be seen as a valued member of his class; to be seen as a person first, not a label; to have the opportunity to be as productive as possible as an adult; and to be a taxpayer, not a tax burden.

The "how do we get there" part took a little more time and required a lot of effort from us and our school team. Some of the components that were essential to establish at the beginning were the development of an appropriate IEP; involving our entire school team; disability awareness activities with students and staff; flexibility on everyone's part; in-servicing our staff on inclusive education; and weekly team meetings.

Inclusion is not just about including children with disabilities in regular classrooms. It is about schools that celebrate differences; where all children have their needs met; where children learn to live, work, and play side by side.

Inclusion does not end when a person with a disability receives a diploma or certificate of attendance. It spans one's entire life and hopefully touches the lives of many typical people.

Preston's journey into inclusion has touched the lives of many people. He has opened eyes that were once closed and changed attitudes, including my own from time to time. One message Preston continues to give us is, never assume anything. He is now achieving goals I once assumed he would never achieve.

Preston's inclusion has been a succession of challenges, triumphs, laughter, and tears. I would like to recap some of the progressions

that Preston has made over the years so you can better appreciate where he is now.

When Preston first entered Myersville, he couldn't hold his head up for very long, and his hands were completely fisted due to tight muscle tone. But, his friends quickly found ways to bring him out of the passive existence he had come to know so well.

They taught him to do "high fives" so he would open his hands and be very cool at the same time. His friends were addressing his physical therapy goals in a very creative and fun manner. They were also addressing IEP goals such as making eye contact and following directions.

Much of his first year was spent learning social skills such as making eye contact; saying, "Hi"; looking at his teacher when she was talking; and learning not to yell out in class. His classmates played a major role in helping Preston with these goals, for he related to his new friends much quicker than he did to adults.

We established a learning buddy system that is still being used quite successfully today. We also tried many different types of adaptive switches in order to find an appropriate communication system.

We saw a different personality emerge. Preston became very demanding at home because he was now in an environment that demanded something from him. His first year also included birthday parties, soccer games, and weekend visits from friends, all new experiences for Preston.

All of Preston's achievements during his first year were goals that were never met at his segregated school. I was so pleased by all the positive changes in Preston during his first year, I didn't think that it could get any better, but it did.

His second year can best be described as a year of surprises. Preston spoke his first real words; he said his name; told the school secretary, "You're welcome"; and said, "Purple," when he saw his purple color card. This was pretty amazing for a boy who was never supposed to live, let alone make a sound.

Through the use of an eye gaze system, we discovered Preston could identify spelling words. We also used this system for number and color cards and for curriculum adaptations.

I am convinced, beyond a shadow of a doubt, that Preston would not be speaking or doing so well academically if it weren't for the continuous reinforcement from his friends and teachers. A child as motorically involved as Preston can easily become a passive observer if they are not challenged both educationally and socially.

Preston began this year with a brand new communication system. He is using a Macintosh Powerbook that has speech output and auditory scanning. Currently, he is using it to make choices such as yes/no, hi/bye, choosing a peer buddy, and sequencing numbers.

Preston continues to identify new spelling words that are taken from units his class is working in. His classroom teacher has also developed a chart that is sent home on a daily basis that gives me a quick overview of his day.

This year has also brought about the development of a Friendship Club. As children get older, we need to continue to find cre-

ative ways to enhance meaningful relationships. That's what we hope our Friendship Club will accomplish.

Inclusion is a lot of work, but as you have heard today, the benefits far outweigh the effort involved. I would like to conclude by sharing a short story I have written that emphasizes the need for all children to be educated together. It's entitled, "A Garden Variety."

A flower garden is a beautiful sight to behold. Who couldn't appreciate a flower garden? Last Spring I happened to visit my friend who is an avid gardener. She had just finished planting her flower beds.

As she did every year, she planted a beautiful carpet of yellow marigolds, all annuals, on one side of her garden and a magnificent display of lavender, rose, yarrow, and sage, all perennials, on the other side.

Just then a neighbor stopped by to see the finished product. As we walked down through the garden, my friend wanted to show us the marigolds first, but her neighbor replied, "Oh, don't bother. They're just marigolds; they're all the same. If you've seen one, you've seen them all."

Well, I couldn't help but cringe when I heard that remark. For you see, people once overlooked my son for being just a marigold. So I suggested to my friend that she transplant the marigolds into her perennial garden. She didn't know if she could care for them all, for they had such different needs. After all, that's why she separated them.

To her amazement, much of what she needed to do before, she no longer had to do. The perennials and annuals both had unique qualities that helped the other. The perennials kept away certain bugs that used to eat her marigolds and worms that once plagued her perennials wouldn't think of coming near now that the marigolds were there. Everyone benefited by being together.

As she gazed upon her beautiful new garden, she realized that although the perennials were still perennials and the annuals still annuals, somehow in her eyes they now looked different. Had they changed? She thought perhaps they had. The yellow tones of the marigolds somehow looked more intense beside the purple sage and the pale pink rose suddenly seemed brighter beside the yellow marigold.

How easily the different shapes, sizes, and colors all seemed to blend together. It was as if it was always meant to be. So it is with inclusion; like the marigold, our children with disabilities who have been overlooked for so long can take their rightful place.

For there is no plot of ground so rich that only one flower can grow from its soil, just as there is no school so unique that all children cannot thrive within its doors. Because, as my friend realized, and as many parents and educators are realizing, the richness, the beauty, is in the diversity. Thank you.

[The prepared statement of Karen Draper follows:]

STATEMENT OF KAREN DRAPER, MIDDLETOWN, MARYLAND

Good morning, I'm Karen Draper. My husband and I have two wonderful children, they attend their neighborhood school, Myersville Elementary, in Frederick County. Our daughter, Samantha, is six and is in the first grade, she is very bright, strong-willed, and funny. She is also very sweet and sensitive to other people's needs.

This, I'm sure, is due in part to her brother.

Preston is 10, he is in the fourth grade and has been fully included for three years. He is smart, stubborn, he has a temper to match his red hair and has a wonderful sense of humor. He also has severe spastic quadriplegic Cerebral Palsy—which means that he is virtually trapped in a body that doesn't work very well. Preston uses a wheelchair. I'm happy to say I can no longer describe him as completely nonverbal, but he does have a very limited vocabulary right now, he needs a computer to communicate, has a mild seizure disorder, mental retardation, and some visual impairments. With all this ... I am often asked—why inclusion? My answer is always another question—why exclusion? When is it ever right to exclude children from their natural environments, such as neighborhood schools, age-appropriate friends, community functions, soccer games, birthday parties, the list is endless.

To gain the answer to this question, our family traveled a long journey that eventually led us right back to where we started from ... our home, our community. Our journey into inclusion began July 19, 1983, the day Preston was born, due to the fact that we almost lost him several times after his birth, we were so thankful to finally have Preston with us and healthy.

As happy as we were, I couldn't help but notice the stares, the quick glances away and as Preston grew older and required a wheelchair, it became painfully obvious that society as a whole was uncomfortable by his presence. That they didn't know how to talk to him, or even if they could talk to him so the solution was to turn away. At that time, we were still living in the world of exclusion, and I can tell you firsthand it was a very lonely world.

You see, when Preston was born he was not only given a NAME by his father and I, but he was given a label by society and because of this label he was put into various categories, categories that were usually about what he couldn't do and what we should never expect him to do because his label of Severely and Profoundly Handicapped said so.

When it was time for Preston to begin his formal education, we were told that he needed to go to a special school for handicapped children. And at that time we did not realize that we even had a choice. This is not a criticism of segregated schools—I realize that by law there needs to be a continuum of services for parents who choose not to include their children in all aspects of the community. But for us it was one more form of excluding Preston from the *natural* daily happenings that his younger sister Samantha was beginning to experience. As our daughter entered her preschool, it became clear that our children's worlds were completely different and that neither understood or felt comfortable with the other. We constantly had to explain Preston to everyone because no one had an opportunity to get to know him. He was *always* seen as a visitor, not a part of a group. We found ourselves always trying to find ways to fit him in instead of him fitting and growing into the community naturally like his sister. The separateness that segregation brought *never* felt right.

In reaching our decision to take Preston out of his segregated environment of five nonverbal classmates into a fully inclusive classroom of 23 very verbal classmates, I researched the pros and cons of inclusive education thoroughly, and in doing so we first had to realize what our vision was. FIRST, What kind of future did we want for Preston, and, SECOND—how do we get there. Our vision was easy to establish. It was built on the fundamental belief that it was Preston's civil right to attend his neighborhood school and should not be a *privilege* for those considered less than perfect. It was also our belief that limited expectations would further disable an already disabled child.

- We want Preston to be a part of his community;
- To have friends that he could interact with at an educational and social level;
- To be exposed to a wide range of activities, people, environments, and ideas;
- To become involved in social activities outside of school;
- To attend school with his sister;
- To be seen as a valued member of his class;
- To be seen as a person first, not a label;
- To have the opportunity to be as productive as possible as an adult;
- To be a taxpayer, not a tax burden;
- And last but certainly not least, to enjoy life to the fullest.

The how do we get there part took a little more time and required a lot of effort from ourselves and our school team. Some of the components that were essential to establish at the beginning were:

- Developing of an appropriate IEP;
- Involving our entire team;

- Disability Awareness activities with students and staff;
- Flexibility on everyone's part;
- In-servicing staff on inclusive education;
- Communication between home and school on a consistent basis;
- Weekly team meetings.

I've just touched on some very basic things that need to occur in order for your school to maintain quality inclusive classrooms. We need to remember that inclusion is a process that parents and teachers *need* to go through, it does not happen overnight. As principals you play a major role in ensuring that everyone understands your vision of how you will attain an inclusive school philosophy. Inclusion is not just about including children with disabilities in regular classrooms, it is about schools that celebrate differences; where all children have their needs met; where children learn to live, work, and play side by side. Inclusion is a place where everyone belongs, it is your community church, the corner store, your neighborhood school, your local park, your workplace. Inclusion does not end when the school bell rings, it carries over into afterschool activities. Inclusion does not end when a person with disabilities receives their diploma or certificate of attendance. It spans one's entire life and hopefully touches the lives of many typical people.

Preston's journey into inclusion *has* touched the lives of many people, he has opened eyes that were once closed and changed attitudes—including my own from time to time. One message Preston continues to give us is, "NEVER ASSUME ANYTHING." He is now achieving goals I once assumed he would never achieve.

Preston's inclusion has been a succession of challenges, triumphs, laughter, and tears. I'd like to recap some of the progressions that Preston has made over the years so you can better appreciate where he is now.

When Preston first entered Myersville, he couldn't hold his head up for very long, and his hands were completely fisted due to tight muscle tone. But, his friends quickly found ways to bring him out of the passive existence he had come to know so well. They taught him to do Hi 5s so he would open his hands and be very cool at the same time. His friends were addressing his PT goals in a very creative and fun manner. They were also addressing IEP goals such as making eye contact and following directions. Much of his first year was spent learning social skills such as making eye contact, saying "hi," looking at his teacher when she was talking, and learning not to yell out in class. His classmates played a major role in helping Preston with these goals, for he related to his new friends much quicker than he did to adults. We established a learning buddy system that is still being used quite successfully.

We also tried many different types of adaptive switches in order to find an appropriate communication system. We saw a different personality emerge. Preston became very demanding at home because he was now in an environment that demanded something from him. His first year also included birthday parties, soccer games, and weekend visits from friends—all *new* experiences for Preston.

I was so pleased by all the positive changes in Preston during his first year, I didn't think that it could get any better, but it did . . .

His second year can best be described as a year of surprises. Preston spoke his first real words; he said his name; told the school secretary, "You're welcome"; and said, "Purple," when he saw his purple color card. This was pretty amazing for a boy who was never supposed make a *sound*!

Through the use of a Language Master we discovered Preston could identify spelling words using an eye gaze and pointing system. We also used this system for number and color cards and for curriculum adaptations. The year ended with an Inclusion Celebration, the students all took part in telling about Preston's newfound skills while he demonstrated them. I am convinced, beyond a shadow of a doubt, that Preston would not be speaking or doing so well if it weren't for the continuous reinforcement from his friends and teachers. A child as motorically involved as Preston can easily become a passive observer if they are not challenged both educationally and socially.

Preston began this year with a brand new communication system. He is using a Macintosh Powerbook that has speech output and auditory scanning. Currently, he is using it to make choices such as Yes/No, Hi/Bye, choosing a buddy, and sequencing numbers. The Powerbook is also reinforcing speech, twice after having used his computer to make a choice he also spoke his answer. It is enabling Preston to control his environment. For a child who has to be fed, dressed and moved from place to place it must be a wonderful feeling to finally have some control. Preston continues to identify new spelling words that are taken from units his class is working in. His classroom teacher also developed a chart that is sent home on a daily basis that gives me a quick overview of his day.

This year has also brought about the development of a Friendship Club, we are in the process of working out schedules, picking the best time slot and criteria for the club. The children will submit applications as to why they should have a friendship club. They will also submit names for their club—I wanted to find a way to empower Preston in the name selection process, so the entire club will pick the top two names, we will then put them in his Powerbook and Preston will cast his vote. As children get older, we need to continue to find creative ways to enhance meaningful relationships, that's what we hope our Friendship Club will accomplish.

Inclusion is a lot of work, but as you've heard today, the benefits far outweigh the effort involved. I'd like to conclude by sharing a short story I've written. . . .

A flower garden is a beautiful sight to behold . . . Who couldn't appreciate a flower garden? Well, this spring I happened to visit my friend, who is an avid gardener, she had just finished planting her flower beds. As she did every year, she planted a beautiful carpet of yellow marigolds [all annuals] on one side of her garden and a magnificent display of lavender, rose, yarrow, and sage [all perennials] on the other side.

Just then a neighbor stopped by to see the finished product. As we walked down through the garden, my friend wanted to show us the marigolds first, but her neighbor replied, "Oh, don't bother, they're *just* marigolds, they're all the same, if you've seen one, you've seen them all." Well, I couldn't help but cringe when I heard that remark. For you see, people once overlooked my son for being "*Just* a Marigold."

So I suggested to my friend that she transplant the marigolds into her perennial garden. She didn't know if she could care for them all, for they had such *different needs*, after all, that's why she separated them.

To her amazement, much of what she needed to do before, she no longer had to do. The Perennials and Annuals both had unique qualities that helped the other. The perennials kept away certain bugs that used to eat her marigolds and worms that once plagued her perennials wouldn't think of coming near now that the marigolds were there. *Everyone* benefited by being together.

As she gazed upon her beautiful new garden, she realized that although the perennials were *still* perennials and the annuals *still* annuals, somehow in her eyes they now looked different. Had they changed? She thought perhaps they had. The yellow tones of the marigolds somehow looked more intense beside the purple sage and the pale pink rose suddenly seemed brighter beside the yellow marigold.

How easily the different shapes, sizes, and colors all seemed to blend together. It was as if it was always meant to be. And so it is with Inclusion, like the marigold, our children with disabilities who have been overlooked for so long can take their *rightful* place.

For there is no plot of ground so rich that only one flower can grow from its soil. Just as there is no school so unique that all children cannot thrive within its doors.

Because, as my friend realized, and as many parents and educators are realizing . . . The richness, the beauty, is in the DIVERSITY!

Chairman OWENS. Thank you. Ms. Markey.

Ms. MARKEY. Mr. Chairman, Congressman Ballenger, thank you for this opportunity to speak to you on this issue. I'm Ursula Markey and I bring greetings from New Orleans. If you ever get a chance to get down there, come on down. We have great food and great music.

As a veteran of the Civil Rights Movement, I never dreamed I would have to fight for equality and inclusion twice in my lifetime; however, with the birth of our son, Duane, my husband, D.J., and I joined that beleaguered society of African-American parents of children with disabilities who have to cope with the struggle to raise their children in a racist society, as well as face the additional prejudice and barriers associated with their children's disabilities.

My son was identified as having a developmental disability in 1975, the same year Public Law 94–142, now known as the Individuals with Disabilities Education Act, IDEA, became a reality. So you could say Duane and the law came of age together, but not without much struggle and not without much still left to learn.

One of the first things we realized back in 1975 was that there was no outreach to parents of children with special needs, at least none to the African-American community, and early intervention was unheard of.

As a result, we lost those first two years after Duane was diagnosed to a series of failed private school placements and our own fear, grief, and isolation. I can still recall the feelings I had when Duane went through the screening and evaluation process 18 years ago.

It was a time when deep and hostile divisions characterized relationships between the races in the South. Although civil rights legislation had been in place for 10 years, it did little by itself to change the negative attitudes toward African-Americans. Services that were offered were offered grudgingly and usually without support or encouragement.

There were, of course, no African-American professionals involved in any aspect of Duane's evaluations. Consequently, it was extremely difficult to disclose personal information about myself, my family, and my child to a stranger of another race, who I had no reason to believe could relate to my people and who I had no reason whatsoever to trust.

I remember leaving Duane's intake meeting trembling, not knowing how the information I provided would be used or who would see it, and feeling that I had somehow betrayed my child. I felt even worse, though, after the screening process began because I realized I had set something in motion that was now beyond my control.

The white-jacketed professionals who conducted the tests appeared distant and cold, and because I was not allowed to observe the testing in progress, I could only imagine how Duane was responding to them and what judgments they were making.

I remember one session that ended early because Duane refused to cooperate with the examiner. My father had come to give us a ride home. As soon as Duane saw my father, he ran to him and hugged him and began to talk and sing. The examiner was shocked because he had never before seen Duane initiate physical contact or engage in meaningful dialogue.

I thought then what a comfort my father could have been to Duane and me, what insights he could have provided, what skills and positive behaviors the evaluators were not able to observe because the testing was done in isolation from our family.

Results of the evaluations were mailed to us without the benefit of explanation, and we didn't always understand the information or the terminology contained in them. Answers to our questions might as well have been spoken in a foreign language, and, in frustration, we sometimes signed paperwork we didn't fully comprehend.

Those early evaluations were largely inconclusive, except in determining that Duane was experiencing an auditory processing problem and could probably benefit from speech therapy; however, for the first two years after Duane entered the public school system, the District was unable to hire a therapist to offer this service.

Duane's behavior was becoming increasingly hard to manage, and the school psychologist's solution to our child's disruptive behavior was the prescription drug Ritalin. We refused that potent

medication, opting instead for behavior management classes offered on a sliding scale fee basis through our public mental health center. Today, affordable behavior management training is no longer available to parents in our community.

In 1980 we fled the South and moved to Los Angeles to help find some help for our son. We soon discovered that the world of special education was no more parent-friendly or accessible there than it was back home. In fact, during the four years we lived in California, Duane was evaluated more than he was educated. While there, he also suffered five inappropriate placements, and we found ourselves in an educational trial-and-error nightmare.

We were parents ignorant of our rights and hopelessly lost in the special education maze. By then we were too tired to even devote time to our marriage or any kind of social life. All those failed placements led to loss of steady income. Somebody always had to be home to supervise Duane when he was between placements, and financial pressure mounted.

We were desperate and considering an out-of-home placement for Duane when an associate at work told us about the Diagnostic School for Neurologically Handicapped Children in Los Angeles. This was a state-of-the-art residential facility where children with difficult-to-diagnose development disabilities received intensive testing and evaluation over a three-month period.

It was one of only three such facilities in the Nation, and it was located right in the place where we lived. Yet, in all those years of failed placements, the Diagnostic School was a resource never offered to us.

Having discovered it, though, we became energized and endured the nearly six-month application process in hopes of receiving a definitive diagnosis and remediation plan for Duane at last. Once Duane entered school—the Diagnostic School, that is—the direct care staff, mostly African-American and Hispanic, whispered to us that they had never seen a black or brown child attend the school.

Duane's stay at the Diagnostic School was nearly over when we received news of our parents' declining health back home. We decided to return home in 1984, armed with Duane's new diagnosis of pervasive developmental disorder and individualized goals and objectives developed by the professionals at the Diagnostic School.

Despite forwarding all this information to the New Orleans Public Schools, school officials acted as if they had never heard of us when we returned home. We were informed that the evaluation from the Diagnostic School was invalid in Louisiana and that yet another evaluation was required by law. Duane was now 12 years old.

After the new evaluation was done, the District's multidisciplinary team recommended Duane be classified as autistic, the District refused to accept the recommendations of its own team.

You see, there were no classes in place in the school system to serve a child with Duane's needs, and rather than create an individualized program for him, we believe the District attempted to change his classification in order to place him in an existing program.

We realized then that we were in serious need of legal advice, but we didn't have the money to hire an attorney. Our local public

legal assistance agency referred us to the fledgling Advocacy Center for the Elderly and Disabled. For the first time, we had the help of someone who understood special education law.

Jim Comstock-Gallagan, an attorney with the Center, became our guide in successfully negotiating the system. We learned we had the right to refuse to sign an Individualized Education Plan and to reject placements that were unacceptable to us.

We learned our rights as parents and used them to insist that the school system create or find an acceptable placement. It took going to due process before we achieved that goal, but Duane was finally enrolled in an excellent program in a neighboring district.

Now I need to explain that during the due process, we actually won the right to place Duane in a special school—a special segregated school, and we really thought that was the way to go because he had been evaluated so much and never had the benefit of instruction. We thought if we could place him somewhere with this, intense instruction could occur; that we would somehow make up for those years that he was lost in the system.

During the course of the due process, we learned about community-based instruction, and though we won the right to have him placed and have that placement in a special school financed by a local school system, we realized that what we were about to do was to remove our son from his community to teach him how to function in it.

It occurred to us that that segregated setting was not going to prepare him to function in his community.

We had become knowledgeable and empowered through Jim's tireless explanation of the law, coupled with the practical application of that law toward a viable plan for Duane. In today's climate of decreased funding, that kind of one-on-one legal advocacy is rarely available to parents.

The more we learned, the more we realized how little school officials and teachers knew about special education law; how much lost time, confusion, and miseducation resulted from this lack of understanding of the law.

We joined the movement for integration of students with disabilities into regular classroom settings in a system that was still largely resistant to racial integration. We knew it would be difficult to send Duane into a regular classroom where he would immediately be identified as "different," and we knew other children could be cruel sometimes.

For the first time, though, we understood what our parents must have gone through, helping us face those days when racial integration first came to public schools in the South. We had come to understand now what they understood then, that separate but equal can never truly be equal and that total integration and participation in mainstream education in America are rights worth fighting for.

We insisted that Duane's program include more opportunities for interaction with his nondisabled peers. The new placement was not without its challenges, and our newly acquired knowledge of special education law protected Duane from proposed suspensions due to behaviors associated with his autism.

Too many youngsters with disruptive behaviors associated with their disabilities still do not have social/behavioral goals and behavior plans included in their IEPs. In Louisiana there are currently no students classified "behavior disordered" or "emotionally disturbed," age 17 or older, who remain in the public school system. What's happened to them? Where are they?

Throughout the years my husband and I have shared what we have learned with other parents whenever we have the opportunity; however, such opportunities are infrequent as the majority of the parent trainings are offered by predominantly white, middle-class agencies to already organized groups of parents that are often composed exclusively of white, middle-class people.

I was once hired to do minority outreach with a local parent training agency; however, before I could begin work, the agency's funding was reduced and they eliminated minority outreach from their budget.

Our son is now 21 and in the last year of his community-based high school program. Our knowledge and application of IDEA has meant everything in finally securing quality special education programs and services for Duane. Our son now lives in an apartment attached to our home and receives personal care attendant and independent living skills support through the Federal Title XIX Waiver Service Program.

Because we availed ourselves of transition planning three years ago, Duane has experienced working in numerous job settings. He has become proficient in computer data entry and currently performs general office duties at the Twomey Center for Peace and Justice at Loyola University in New Orleans.

We believe his education is preparing him to take full advantage of the rights guaranteed by the Americans with Disabilities Act and to live successfully in his community.

Presently, my husband and I own and operate Proactive Case Management, Incorporated, an independent service coordination agency that serves Medicaid recipients who have developmental disabilities. Our services include assisting parents in the IEP process. Thus far, during this school year, I have participated in 13 IEP meetings, 11 of which involved African-American students.

It is disheartening to see these parents facing many of the same obstacles my family encountered 18 years ago. Sadly, school administrators and teachers, though often well-intentioned, still do not demonstrate working knowledge of IDEA and continue to disseminate erroneous information that undermines the law.

Parents, especially those of traditionally underserved populations who have not yet fully grasped the basics of IDEA, are having to make difficult decisions about new concepts such as inclusion.

These parents and their children are at risk of losing important and necessary related services when they don't understand their rights, and school systems sometimes use inclusion as a means of cutting the costs of providing individualized related services to children.

African-American and Hispanic parents are increasingly forced into the debate regarding the over and under referral of our children into special education. The debate rages, while we are losing sight of individualized programming, the hallmark of IDEA, that

ensures that each child is seen as an individual and that programs are written and implemented accordingly.

Just last week I participated in my first meeting as a member of the New Orleans Public Schools Special Education Advisory Council. The invitation was extended due to a Federal mandate requiring an increased participation of parents on such councils. The new council, energized by parents determined to enact meaningful positive change, is ready to move toward true reform in special education.

For the past 18 years, the Individuals with Disabilities Education Act, IDEA, has been just that, a great idea. With new creative approaches in outreach to underserved parents and funding of those new approaches, and provision of the much needed training for school officials, teachers, cultural mediators, related services providers, and all parents of children with special needs, IDEA will, at last, be a reality whose time has come.

[The prepared statement of Ursula Markey follows:]

STATEMENT OF URSULA MARKEY, NEW ORLEANS, LOUISIANA

As a veteran of the Civil Rights Movement, I never dreamed I would have to fight for equality and inclusion twice in my lifetime. However, with the birth of our son, Duane, my husband, D.J., and I joined that beleaguered society of African-American parents of children with disabilities who have to cope with the struggle to raise our children in a racist society, as well as face the additional prejudice and barriers associated with their children's disabilities.

My son was identified as having a developmental disability in 1975, the same year Public Law 94–142, now known as the Individuals with Disabilities Education Act [IDEA] became a reality. So you could say Duane and the law came of age together, but not without much struggle and not without a lot still left to learn.

One of the first things we realized in 1975 was that there was no outreach to parents of children with special needs, at least none to the African-American parents, and early intervention was unheard of in our community. As a result, we lost the first two years after Duane was diagnosed to a series of failed private school placements and our own fear, grief, confusionm and isolation.

I can still recall the feelings I experienced when Duane went through the screening and evaluation process 18 years ago. It was a time when deep and hostile divisions characterized relationships between the races in the south. Although civil rights legislation had been in place for 10 years, it did little to change the negative attitudes towards African-Americans. Services were offered grudgingly and usually without support or encouragement.

There were, of course, no African-American professionals involved in any aspect of Duane's evaluations. Consequently, it was extremely difficult to disclose personal information about myself, my family, and my child to a stranger of another race, who I had no reason to believe could relate to my people and who I had no reason whatsoever to trust. I remember leaving Duane's intake meeting trembling, not knowing how the information I provided would be used, or who would see it, and feeling that I had somehow betrayed my child.

I felt even worse after the screening process began because I realized I had set something in motion that was now beyond my control. The white-jacketed professionals who conducted the tests appeared distant and cold, and because I was not allowed to observe the testing in progress, I could only imagine how Duane was responding to them and what judgments they were making.

I remember one session that ended early because Duane refused to cooperate with the examiner. My father had come to give us a ride home. As soon as Duane saw my father, he ran to him and hugged him and began to talk and sing. The examiner was shocked because he had never before seen Duane initiate physical contact or engage in meaningful dialogue. I thought then what a comfort my father could have been to Duane and me, what insights he could have provided, what skills and positive behaviors the evaluators were not able to observe because the testing was done in isolation from our family.

Results of the evaluations were mailed to us without the benefit of explanation and we didn't always understand the information or the terminology contained in them. Answers to our questions might as well have been spoken in a foreign lan-

guage and in frustration we sometimes signed paperwork we didn't fully comprehend.

Those early evaluations were largely inconclusive, except in determining that Duane was experiencing an auditory processing problem and could probably benefit from speech therapy. However, for the first two years after Duane entered the public school system, the District was unable to hire a therapist to offer this service. Duane's behavior was becoming increasingly hard to manage and the school psychologist's solution to our child's disruptive behavior was the prescription drug Ritalin. We refused that potent medication, opting instead for behavior management classes offered on a sliding scale fee basis through our public mental health center. Today, affordable behavior management training is no longer available to parents in our community.

In 1980 we fled the south and moved to Los Angeles to find help for our son. We soon discovered that the world of special education was no more parent-friendly or accessible there than it was back home. In fact, during the four years we lived in California, Duane was evaluated more than he was educated. While there, he also suffered five inappropriate placements. It was an educational "trial-and-error" nightmare.

We were parents ignorant of our rights and hopelessly lost in the special education maze. We were too tired to devote time to our marriage or any kind of social life. All those failed placements led to loss of steady income—somebody always had to be home to supervise Duane when he was between placements—and financial pressures mounted.

We were desperate and considering an out-of-home placement for Duane when an associate at work told us about the Diagnostic School for Neurologically Handicapped Children in Los Angeles. This was a state-of-the-art residential facility where children with difficult-to-diagnose developmental disabilities received intensive testing and evaluation over a three-month period. It was one of only three such facilities in the Nation, and it was located right in the place where we lived.

Yet, in all those years of failed placements, the Diagnostic School was a resource never offered to us. Having discovered it, we became energized and endured the nearly six-month application and acceptance process in hopes of receiving a definitive diagnosis and remediation plan at last. Once Duane entered school, direct care staff, mostly African-American and Hispanic, whispered to us that they had never seen a black or brown child attend the school.

Duane's stay at the Diagnostic School was nearly over when we received news of our parents' declining health back home. We decided to return home in 1984, armed with Duane's new diagnosis of Pervasive Developmental Disorder, and individualized educational goals and objectives developed by the professionals at the Diagnostic School.

Despite forwarding all of this information to the New Orleans Public Schools, school officials acted as if they had never heard of us when we arrived home. We were informed that the evaluation from the Diagnostic School was invalid in Louisiana and that yet another evaluation was required by law. Duane was now 12 years old.

When, after the new evaluation was done, the District's multidisciplinary team recommended Duane be classified as autistic, the District refused to accept the recommendations of its own team. There were no classes in place in the school system to serve a child with Duane's needs, and rather than create an individualized program for him, we believe the District attempted to change his classification in order to place him in an existing program.

We realized we were in need of serious legal advice but we didn't have the money to hire an attorney. Our local public legal assistance agency referred us to the fledgling Advocacy Center for the Elderly and Disabled. For the first time we had the help of someone who understood special education legislation

Jim Comstock-Gallagan, an attorney with the Center, became our guide in successfully negotiating the system. We learned we had the right to refuse to sign Individualized Education Plans [IEPs] and to reject placements that were unacceptable to us. We learned our rights as parents and used them to insist that the school system create or find an acceptable placement. It took going to due process before we achieved that goal, but Duane was finally enrolled in an excellent program in a predominantly Anglo-American neighboring district.

We had become knowledgeable and empowered through Jim's tireless explanation of the law, coupled with the practical application of that law toward a viable plan for Duane. In today's climate of decreased funding, the kind of one-on-one legal advocacy we received is rarely available to parents.

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The more we learned, the more we realized how little school officials and teachers knew about special education law—how much lost time, confusion, and miseducation resulted from this lack of understanding of the law.

We joined the movement for integration of students with disabilities into regular classroom settings in a system that was still largely resistant to racial integration. We knew it would be difficult to send Duane into a regular classroom where he would be immediately identified as "different" and we knew other children could be cruel sometimes. For the first time we understood what our parents must have gone through, helping us face those days when racial integration first came to public schools in the south. But we had come to understand now what they understood then, that separate but equal can never truly be equal and that total integration and participation in mainstream America are rights worth fighting for.

We insisted that Duane's program include more opportunities for interaction with his nondisabled peers. The new placement was not without its challenges, and our newly acquired knowledge of special education law protected Duane from proposed suspensions due to behaviors associated with his autism. Too many youngsters with disruptive behaviors associated with their disabilities still do not have social/behavioral goals and behavior plans included in their IEPs. In Louisiana there are currently no students classified Behavior Disordered or Emotionally Disturbed, age 17 or older, who remain in the public school system. What has happened to them? Where are they now?

Throughout the years my husband and I have shared what we have learned with other parents whenever we have the opportunity. However, such opportunities are infrequent as the majority of the parent trainings are offered by predominantly white, middle-class agencies to already organized groups of parents that are often composed exclusively of white, middle-class people. I was once hired to do minority outreach with a local parent training agency. However, before I could begin work, the agency's funding was reduced and they eliminated minority outreach from their budget.

Our son is now 21 and in the last year of his community-based high school program. Our knowledge and application of IDEA has meant everything in finally securing quality special education programs and services for Duane. Our son now lives in an apartment attached to our home and receives personal care attendant and independent living skills support through the Federal Title XIX Waiver Program.

Because we availed ourselves of transition planning three years ago, Duane has experienced working in numerous job settings. He has become proficient in computer data entry and currently performs general office duties at the Twomey Center for Peace and Justice at Loyola University in New Orleans. We believe his education has prepared him to take full advantage of rights guaranteed by the Americans with Disabilities Act and to live successfully in the community.

Presently, my husband and I own and operate Proactive Case Management, Inc., an independent service coordination agency that serves Medicaid recipients who have developmental disabilities. Our services include assisting parents in IEP conferences. Thus far, during this school year, I have participated in 13 IEP meetings, 11 of which involved African-American students. It is disheartening to see these parents facing many of the same obstacles my family encountered 18 years ago. Sadly, school administrators and teachers, though often well-intentioned, still do not demonstrate working knowledge of IDEA and continue to disseminate erroneous information that undermines the law.

Parents, especially those of traditionally underserved populations, who have not yet fully grasped the basics of IDEA, are having to make decisions about new concepts such as inclusion. These parents and their children are at risk of losing important and necessary related services when school systems use inclusion as a means of cutting the costs of providing individualized related services to children.

African-American and Hispanic parents are increasingly forced into the debate regarding the over and under referral of our children into special education. The debate rages while we are losing sight of individualized programming, the hallmark of IDEA, that ensures that each child is seen as an individual and that programs are written and implemented accordingly.

Just last week I participated in my first meeting as a member of the New Orleans Public Schools Special Education Advisory Council. The invitation was extended due to a Federal mandate requiring the increased participation of parents on such councils. The new council, energized by parents determined to enact meaningful positive change, is ready to move toward true reform in special education.

For the past 18 years, the Individuals with Disabilities Education Act, IDEA, has been just that—a great idea. With new creative approaches in outreach to underserved parents and provision of much needed training for school officials, teachers,

cultural mediators, related services providers, and ALL parents of children with special needs—IDEA will, at last, be a reality whose time has come.

Chairman OWENS. Thank you. Ms. Gerhardt.

Ms. GERHARDT. Congressman, thank you for allowing me to speak with you today. My name is Jeanne Gerhardt. I am from Hickory, North Carolina, and I have four children, all who attend school in the Hickory City school system. My daughter Sarah is my third child. She is 12 years old, in the sixth grade, and is learning disabled.

When Sarah was four years old, we had her speech and hearing tested through the Crippled Children's Speech and Hearing Clinic. They suggested that we seek further evaluation through the Developmental Evaluation Center, or DEC, and place her in a playschool to increase stimulation.

This began a series of referrals and evaluations. Each teacher, physician, and therapist recommended some type of assistance for Sarah. Sometimes the recommendations involved practices or exercises that could be done at home or in the classroom, but most times the recommendations included resource or LD placement in school.

When the school was approached, we were repeatedly told that Sarah did not qualify for LD placement because her achievement scores were not at least 15 points below her abilities or IQ.

She was evaluated again by DEC before the start of the third grade. They recommended that the school-based committee consider Sarah's multiple needs in regards to appropriate services. Again, we were told that she did not qualify for placement because there was not a 15-point discrepancy.

Shortly into her third grade year, the teacher expressed concerns about Sarah's ability to keep up with the third grade curriculum. When it came time for the California Achievement Test, or CAT, to be given, we received a letter stating that Sarah had been identified as a child who may have problems with the test.

Up until this point, the school system had insisted that Sarah's problems did not warrant resource placement. Now they were predicting, before she took the test, that she may be unable to score at or above the 25th percentile on a standardized test.

I again asked if the only way for a child to qualify for LD placement was with a 15-point discrepancy, and I was told that it was the only criteria by her speech therapist, her teacher, the LD teacher at the school, principal, the DEC staff, and the Director of Exceptional Children's Programs.

I then called the North Carolina Department of Education to ask about the criteria for LD placement. I was informed that besides the 15-point discrepancy, there was also a procedure called "Documenting a Discrepancy Alternative." This procedure calls for assessment from other sources, parent information, classroom observations, and work samples, all the things that we had considered in pursuing LD placement.

We then met with the Superintendent of Schools and the Director of Exceptional Children's Programs. I asked why we had not been informed previously of the procedure to document a discrepancy alternative and was told, "We don't use that form much." I

was also advised by the superintendent not to push my child too hard or she may learn to resent me.

There was an agreement to reconsider Sarah's education plan after the CAT, and it was indicated that more assistance might be forthcoming. Sarah scored in the 25th percentile on her CAT and therefore would not qualify for remediation. The teacher wrote a strong letter of recommendation, and since there were spaces left, she was accepted into summer school.

In the fourth grade, Sarah was placed in the Chapter 1 reading program based on her CAT scores. She still did not qualify for LD placement. Early in that year, my husband and I attended a conference for parents and teachers of LD and ADD children. We were referred to a physician named Dr. Olsen Huff.

After our first visit he referred us to a neuropsychologist and genetic counselor. It was with the geneticist that we found our answer. Sarah has an anomaly called 18p-Syndrome, which means that there is a shortened arm of her 18th chromosome.

Sarah now qualifies for LD placement as "other health impaired." Her test scores have not changed; her classroom difficulties have not changed; her frustration level has not changed. Now that a label can be put to the problem, she can receive the resource placement that had been repeatedly recommended over the previous seven years.

Prior to the genetic testing, we received the following diagnoses: functioning within the borderline range; visual motor skills significantly below average; adaptive behavior skills significantly below average; central auditory processing difficulties; moderate delay in auditory perceptual skills; neurological problems consistent with minor neurologic dysfunction; moderate visual constructural deficits; motor dyspraxia; substantial impairment in attentional control; and an almost crippling impairment in temporal resolution. All of this meant nothing until we had a name for her problem.

My husband and I do not have a great deal of money. He is a teacher and I am a nurse, and we have paid for a lot of that testing, with minimal help from insurance.

Prior to her correct diagnosis—her final diagnosis—we paid for two speech and hearing evaluations; 2½ years of private speech therapy; a year of preschool that was recommended by Crippled Children's Speech and Hearing Clinic; three evaluations at the DEC; one occupational therapy evaluation; one neurological consult; eight months of seeing a psychologist; four appointments at Thoms Rehabilitation Hospital; three genetic counseling appointments; three genetic studies; an EEG; and eight years of medications for ADD.

We all know that my child is not the only one in this position. What happens to children whose parents are not aware of what resources are available to them? What happens to the children whose parents trust, without questioning, that what the school will do is what is best for their children? What happens to the children whose parents cannot afford to pursue their concerns once the school has said no?

We are not looking at the whole child when the only criteria that we use is test scores. Every learning disabled child is different, just

as every other child is different, and his or her needs cannot always be neatly fitted into a label or category. Thank you.

[The prepared statement of Jeanne Gerhardt follows:]

STATEMENT OF JEANNE GERHARDT, HICKORY, NORTH CAROLINA

My name is Jeanne Gerhardt. I am from Hickory, North Carolina, and have four children, all who attend school in the Hickory City School System. My daughter, Sarah, is my third child. She is 12 years old, in the sixth grade, and is learning disabled [or LD].

When Sarah was four years old, we had her speech and hearing tested through the Crippled Children's Speech and Hearing Clinic. They suggested that we seek further evaluation through the Developmental Evaluation Center [or DEC], and place her in a playschool to increase stimulation.

This began a series of referrals and evaluations. Each teacher, physician, and therapist recommended some type of assistance for Sarah. Sometimes it was practices or exercises that could be done at home or in the classroom, but most times the recommendations included resource or LD placement in school. When the school was approached, we were repeatedly told that Sarah did not qualify for LD placement because her achievement scores were not at least 15 points below her abilities or IQ.

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Early in the fall that year, my husband and I attended a conference for parents and teachers of LD and ADD children. We were referred to a physician named Dr. Olsen Huff. After our first visit he referred us to a neuropsychologist and a genetic counselor. It was with the geneticist that we found our answer. Sarah has an anomaly called 18p-Syndrome—which means that there is a shortened arm of her 18th chromosome.

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All of this meant nothing until we found a name for the problem.

My husband and I do not have a great deal of money. He is a teacher and I am a nurse. We have paid for the following with minimal help from insurance:

2 speech and hearing evaluations;
2½ Years of private speech therapy;
1 Year of preschool recommended by the Crippled Children's Speech and Hearing Clinic;
3 Evaluations at the Developmental Evaluation Center;
1 Occupational therapy evaluation;
1 Neurological consult;
8 Months of seeing a psychologist;
4 Appointments at Thoms Rehabilitation Hospital;
3 Genetic counseling appointments;
3 Genetic studies;
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Chairman OWENS. Thank you. I want to thank you all for your testimony. It's been very informative. I'll start with this question: Where do you feel the finger of the Federal Government is helping you with some of the problems that you have encountered? Ms. Gerhardt and Ms. Markey, do you ever feel any Federal Government presence; the Department of Education?

Ms. MARKEY. Well, I would say, when the Advocacy Center was doing case management—and they received Federal funds to help parents. Unfortunately, they have turned their attention to systems advocacy because of a reduction in their funding, and so——

Chairman OWENS. Systems advocates means what?

Ms. MARKEY. They're not taking the individual cases and working on those things that affect the system. For example, right now in New Orleans we're facing a situation where parents are being told that their children cannot receive speech therapy services when the child's speech level is commensurate with his overall functioning ability. The Advocacy Center is addressing that on a systems level because it's really illegal.

Chairman OWENS. Have either of you ever had concrete assistance that you could attribute to the Federal Government in working your way through your problems?

Ms. GERHARDT. At one point I was given an article by the psychologist that we were seeing, about a child in North Carolina who had similar problems to Sarah. At the end of the article, it said if you have similar problems, send them to, and they gave the address of the Office of Civil Rights for the Department of Education.

So they called and offered to send a mediator, and that's when I found myself in the superintendent's office. He, at that point, ex-

pressed a willingness to take a second look at this. So we dropped mediation and really didn't get much of a second look.

Ms. MARKEY. I would like to add that under Medicaid and the Title XIX program, the Title XIX Medicaid Waiver Program is the one that allows people who would ordinarily be qualified to be placed in institutions, to remain in the community.

In our own case management practice, we use those funds. At least Medicaid pays us to access community services, and one of those services will be, of course, the educational system.

So we have been able to assist parents with IEP meetings, but there are so few people who know that that's available to them. That's not to say that all of the independent case managers have the background in the law that we have.

So, at last, we are being paid through Medicaid to help—to do what we were already doing without pay, but it's still reaching far too few people. They don't know about this under Medicaid, and even the case managers are not prepared to help them to the fullest extent.

Chairman OWENS. Ms. Draper and Mr. Rosenberg, would you like to have an Oxford-style debate?

[Laughter.]

Mr. BALLENGER. That's great.

Chairman OWENS. These two approaches are mutually exclusive. Mr. Rosenberg, I am curious about the model schools you described. You said that there's another one like the one your son is in?

Mr. ROSENBERG. Yes.

Chairman OWENS. They're both in the same school system?

Mr. ROSENBERG. That's correct.

Chairman OWENS. How many students does each school have?

Mr. ROSENBERG. I believe that——

Chairman OWENS. Do you want to push the mike over?

Mr. ROSENBERG. Sure. I believe that Longview has approximately 50 to 55 students. It's the school that is located in the upper part of the county. There's another school—Stephen Knolls—that has an identical population. That's in the lower part of the county and has about the same number of students, maybe about 10 more.

Chairman OWENS. In your opinion, what would happen if the school—that you described as an excellent one for your child—were to expand, bringing in regular classes and other students?

The inclusiveness would be provided, but you build inclusiveness around a program that's already centered on students with disabilities. What would be the likely result, in your opinion?

Mr. ROSENBERG. I think that if there are practical considerations that were adequately taken into account, it's a doable suggestion.

What I mean by that is, if the same benefits of centralization were available—you had the school in a sufficiently separate area where the problems of distractibility that were so evidently brought up with the bells earlier today—we wouldn't have that kind of problem, where the inclusiveness could be adjusted when appropriate.

I don't think that there's a problem with doing that. One of the concerns that I would have is that the integrity of the program be maintained.

One of the problems that I know occurs at times, when you have a school within a school, which is what I think you're driving at, is whether the principal of that special education program or the person who's administering it is able to maintain control.

Some of the organization feel that the concern our principal has for our program would be lost, especially if that administration received someone who had many other responsibilities.

Chairman OWENS. Would you respond to that, Ms. Draper?

Ms. DRAPER. Yes, in terms of communication and overseeing what is happening within a school, I have more communication with my son's neighborhood school than I ever had at a segregated school. I found that in a segregated school, everyone became kind of like a family, so comfortable that there was no accountability.

With quality inclusion, not just by merely placing a child in a regular classroom, we have weekly team meetings which include our occupational therapist, our physical therapist, our special education teacher, our classroom teacher, and our principal who joins in every other week. So there's communication, and he is able to oversee what is happening within that program.

Chairman OWENS. You both are in situations where your children's needs are being met and you are pretty satisfied with the way the program operates. The other two parents here and the panelists we heard earlier have situations where that basic resource is not there.

There's a great debate raging, of course, about resources and how we're going to be able to stretch out those that are available now. We need the Federal Government to provide more resources. How those resources are utilized—those that exist already and those we add—is a critical question.

This whole debate on more inclusiveness versus more specialized segregated settings, is the basic question. If we don't let our legislation deal with it, local governments are going to deal with it for us.

We're going to have to make some definite decisions in terms of addressing the pressures that are mounting. Most of the pressures move in the direction of more inclusion because it saves money, and I don't think either one of you approve of that.

I don't think anybody here would approve of having the problem solved in a way which just saves the most money, and, accidentally might help some kids and might harm others. So we would like to have your advice on how to reach the proper middle ground.

Ms. Markey, you said Medicaid becomes a possibility in terms of aiding students in certain categories. That's not widely known. It provides another resource that can be factored into the equation when you are trying to find out the best way to provide the services.

The whole question of how to give your children a real opportunity to learn with the right teachers and the right classroom setting, the right environment—Mr. Rosenberg talked about how it's important that the environment not be too distractive—the right kind of equipment, et cetera means that we need your advice on ways to come up with the model system, the best approach.

Ms. MARKEY. I think the hallmark, as I said, is individualized planning and instruction. I think that's lost a lot of times because,

first of all, parents don't know the law and because teachers don't know the law.

I go into IEP meetings now, and that same erroneous information is being given. You have a feeling, though, that even if you come up with a really good IEP that is individualized for that child, that the teacher takes the IEP, takes it to a file cabinet in her class, and files it away.

Then the program goes on as always, with teaching to all the kids in the same way. If we can focus on that and monitor the way a program is run—right now, if parents aren't able to monitor, nobody's got an eye out on whether the program you spend all your time in the IEP meeting developing and individualizing, is ever carried out.

When problems arise, the person who's brought in to settle the problem is usually the school principal, who has not even been trained in special education law. So then that principal turns to the teacher and says, "Is this being done correctly?" So the teacher gets to monitor herself.

So, if parents aren't trained, they cannot go in that room and realize that measurable behavioral objectives are a way that we can measure progress—if the program is working or even being run.

Right now, even though you have a legal document, if you don't know your rights and you don't have access to the data, or the teachers aren't correcting the data, then there's no way to show that it's enforced, except to say, "My kid's not doing any better," and have the sense that nothing is improving.

So, I think the thing we have to stress is, training—training at all levels. It's been 18 years and people still don't know the law. The other thing is that special education is seen as a box, as something that—we talk about inclusion, but then we're not funding the expansion of the concept to the regular education environment.

So Part B moneys—used to train special education, not in the law, just to train them in technique—are not being shared with regular education teachers.

If we're going to talk inclusion, those teachers are out there scared to death about getting children with special needs, and they haven't had any training. The regular education system isn't training them and the special education system isn't training them. So, here we are.

Chairman OWENS. Yes, we have a teacher's union arguing that they don't want inclusion because the teachers have not been trained; it's unfair to put that burden on teachers.

The administrators are pressing, on the other hand, to have inclusion because the present situation's too costly and each spoke about the hostility it encountered as a result of the race. Hostility, with respect to cost, goes on and on and on; it seems to be everywhere. They look upon that program as being a burden.

We do need your help in trying to get a middle ground here, and I think Mr. Rosenberg had a situation where only the alertness of some very active and well-organized parents kept the program from being wiped out, am I right?

Mr. ROSENBERG. That's correct, and what I want to say about that is, this was really quite spontaneous. We had no parent organization in Montgomery County prior to the events that I had de-

scribed, and from our side of the table there is no funding for parent advocacy groups. There's plenty of money out there for parent advocacy groups who want inclusion, but those that feel satisfied with the programs they have—and believe they work well——

Chairman OWENS. Could you elaborate on that? There's money for parents who want inclusion, but no money for other parents?

Mr. ROSENBERG. For advocacy groups, that's certainly the case. In the State of Maryland, there are two organizations that support inclusion: one by mandate and the other in practice. One is the Maryland Coalition for Inclusive Education and the second one is the Maryland Disability Law Center.

Both of those organizations devote most, if not entirely, all of their energies to representing people that want inclusion, and that's fine. When it's appropriate, that's what they ought to be doing.

On our side of the table, though, what we found was that a number of events were occurring and there was nobody speaking on our behalf; we had no paid advocate.

What, in fact, happened was, a number of us—some of us were in the home during the day, some of have jobs during the day outside the home—banded together across disabilities and lobbied the school system and the school board to protect our programs.

One issue that had come up was that the budget for the special programs was being targeted, and we secured a petition of hundreds of families in Montgomery County to oppose the targeting of those items.

We didn't win all of that, but I think it does speak to the fact that there are plenty of people in our school system, and around the country, that have strong feelings about the programs that they have and their excellence.

We had to do it all on our own, and, as we have been told time and again, there was a speeding train running down the track out of control, and had we not shown up when we had, it would have gone the whole way down into the station.

Chairman OWENS. Do you know whether the funds are coming from the Federal Government or State government?

Mr. ROSENBERG. I know they come from both.

Chairman OWENS. Both?

Mr. ROSENBERG. That's correct. In the case of the Maryland Coalition, it comes primarily from Federal funding through the Department of Education and, I think, also through Health and Human Services.

Ms. MARKEY. Well, let me just say, if I may, there isn't a lot of money out there for people who are pushing for inclusion. You know, $50,000—I mean, there isn't money out there for underrepresented parents either. I mean, $50,000 for 50 States and the territories, you know——

Chairman OWENS. Where did you get that figure from?

Ms. MARKEY. I was listening to Ms. Spinkston's testimony.

Chairman OWENS. No, hers is not for advocates for inclusion or exclusion; hers is for technical assistance.

Ms. MARKEY. Oh, I see what you're saying, and I'm taking it as though—the establishment of parent training and information centers in the 50 States has been a wonderful boon to every parent

because the information is now there, but I'm saying the underserved parents—outreach to them—we always talk about the increasing diversity and how concerned we are about those populations, but the funding for outreach to them is not demonstrating that commitment.

Chairman OWENS. Mr. Ballenger.

Mr. BALLENGER. I don't want to ask a whole bunch of questions. In the discussion that we have had here, it appears that everybody we have talked to had an obvious situation, even Mrs. Gerhardt, though she had difficulty in getting somebody to prove it.

Everyone else had an obvious situation that the people could accept, whereas you had a number. You had to get, what is it, 25 percent? Is that a——

Ms. GERHARDT. Fifteen-point discrepancy.

Mr. BALLENGER. Is it normal for the State to require proof that your child needed assistance?

Ms. GERHARDT. Yes.

Mr. BALLENGER. You had a mathematical number that you had to meet. Does that occur in other States?

Ms. SPINKSTON. Yes.

Ms. GERHARDT. At one point in our testing, it showed that Sarah was achieving at 16 points above her IQ, and I asked, "Well, how can that happen, and if it can't, how do we know that the test is that inaccurate? How do we know it's not 15 points below?" I just didn't get an answer.

There were a lot of IEPs that I signed that said, "Signature does not imply agreement," and I signed them that way so that I could show that I was there and that I did——

Mr. BALLENGER. That basic idea is pervasive throughout the country. People that are on the verge or right on the end, or that are not obvious, have difficulty getting in the program. Thank you, Mr. Chairman.

Chairman OWENS. Well, thank you very much for being quite patient. We will certainly make use of your testimony as we conclude the reauthorization of this legislation. If you have any further comments you would like to submit to us, please do so within the next ten days.

I would like to again remind everyone that we will have additional hearings—open mike hearings—set up so that more parents can individually testify. We will notify all the groups that are involved that that opportunity will be made available. Thank you very much. The hearing of the subcommittee is now adjourned.

[The hearing adjourned at 12:19 p.m., subject to the call of the Chair.]

MS LINDA DI CECCO
11 CHALONER COURT
CRANSTON, R.I. 02921

Mr. Chairman and Committee Members:

Thank you for the honor and opportunity to comment as the parent of three special needs students.

First, let me tell you about the newly formed ACTION national coalition -- Action for Children to Insure Options Now. A number of disability organizations and parent advocates (including myself) met and formed this coalition in December 1993 to assure that the full continuum of equal placement options remain a critical component of the Individuals with Disabilities Education Act (IDEA). We are determined to protect and enhance the full continuum of placement options that ensures equitable, meaningful and effective access to education. There are currently 52 organizations in the ACTION coalition, representing and serving children and families across the disability spectrum. This number increases daily.

Now let me tell you briefly about my children. There has been aggressive "mainstreaming/inclusion" in my district and state for about the past five years. I jumped right in, without really knowing what it meant. To translate for new parents - it meant cutting back on or eliminating services and dismantling what few programs there were -- the Least Expensive Environment. Becky, age 16, was declassified by the district to Learning disabled **(first classified Other health impaired - diagnosed with Tourette's syndrome, ADHD, school phobia)**. Failure followed failure. She was medicated during the school year. She is taunted and abused for her disability by her "peers". She had no true support from school authorities. She has been sat on a dunce stool and carrelled for her motor tics and attention disorder -- for her verbal tics, she is continuously kicked out of class, and always has detention. Not coping in this "mainstream", she became hostile -- she was asked to quit school (age 15), and made two suicide gestures. Once she used a razor from Biology Lab -- she was asked for a written apology, nothing else. Psychopharmacological Clinic dropped her because of the medication risk. The system makes us walk a minefield. DJ, age 9, was declassified to Learning disabled **(first classified as Behavior disorder/ developmental delay - diagnosed with autism, middle ear pathology)**. He has come home with black eyes, bite marks, bruises - all with no explanations. Losing programming, especially specific to autism, he is becoming hostile after school, made a suicide gesture, and has even begged me to kill him. He has no placement after June. Dan, age 7, **(first classified Speech-language impaired - diagnosed middle ear pathology, language delay)** was recently declassified to - you guessed it - Learning disabled. Dan once came off the school bus with his teeth imbedded in his lips. I removed him from a class after walking in on him being assaulted by another student. Then nonverbal, he was a perfect victim. My district acts (allegedly following state procedures) without medical diagnosis or my consent. There are **no plans or programs** to be had for my children. I pay dearly when I fight for my children to have a chance. As Earl Warren once said: *"Everything I did in my life that was worthwhile I caught hell for."* After nine hard years in the system **(having met some wonderful teachers and spent about $30,000 in litigation)**, here is what I've learned:

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When a system is out of compliance, parents expecting ACADEMIC PROGRAMS for special needs children are the perceived problem. And *"problems are messages."* Our message is one of desperation - for our children to escape a cycle of academic failure in the tangled web of a vindictive and intrusive system.

In R I , OCR (Region I) recently found in one district that (complaint #01-91-1311, dated 6/10/93):

" -a significant amount of IEP services were not delivered,
-staff signatures to record attendance were submitted to parents as signed agreement to placement changes,
-a climate of intimidation, coercion, harassment, threats, and retaliation for the purpose of interfering with protected rights existed... etc, etc..."

Learning disabled has become the codeword for "declassified." Our children are being systematically declassified. Don't blame teachers, their livelihood is hostage to a system which is out of compliance, just like my children are. The individual procedural safeguards fail us. The due process system works like a SLAPP suit against us. IDEA has not failed us, it just never had a chance with all the noncompliance nonsense. The lowest common denominator of accountability and expertise can only place our children at grave risk.

Children with disabilities do not learn alike. While each group has unique strengths and weaknesses -- it is common within a specific disability group to see a wide disparity in individual needs. This is further complicated by the incidence of multiple disabilities. Fortunately, IDEA recognizes this diversity and guarantees an individual education plan for each student. For some, the regular classroom is the right option. Some function best when all or part of their time is spent in a special class within a regular school. For others, a specialized school provides the only programming from which they can derive educational growth. During the reauthorization, we must make sure that such alternatives continue to exist.

The option of inclusion is protected in what I have described above -- but the inclusionists' strategy is set to destroy the precious full continuum of educational placement options in the Part B regulations for parents like me. "Inclusionists" want their children socialized in the schools -- parents like me want our children educated in the schools. They say "immoral" and "segregation" if we dare to say that education comes first. These "abolitionists" have started a "name-it-and-claim-it" fad using African-American historical terms and my children's civil rights. Martin Luther King described such people well when he said *"Shallow understanding from people of good will is more bewildering than outright rejection."* The intent of Congress and the spirit of the law can be thwarted by adopting any fad without due diligence.

The two historical methods used to dominate a vulnerable population were the exclusion method and the inclusion method. Who would choose either? When this inclusion movement plays out, "regular" education could garner our combined assets, as our children sit on the fringes for the dubious pleasure of "socialization."

IDEA is our own piece of history that must remain intact for all children with disabilities who seek an education.

As you undertake the reauthorization review, keep not just my children, but the millions of others, in mind -- and protect the full range of educational choices they need.

My children can learn. I hope for that day when my children will have the same opportunities as yours...

My recommendations for reauthorization review:

- Make the system consumer-driven and make IEPs signed documents
- Insure educational service to the underserved or unserved (learning disabled, neurologically or mental health impaired, deaf, blind ...).
- Expand OCR's role - move from litigation to a compliance model
- Move towards 40% federal funding.
- Distinguish neurologic and mental health needs from learning disabled.
- Don't trap unstable children in nontherapeutic settings (**stay-put rule**)
- Follow-up over-16, out-of-school, special needs children.
- Return to an accountable and uncompromised medical model. The school system is unqualified to medically "diagnose".
- The medically fragile must be responsibly handled.
- Overhaul IDEA regarding compliance, interagency agreements, coordination of funding streams and state/local advisory panels.
- Allow only medical/social/psychological data *which are educationally relevant and make the system professionally accountable.*
- Cost and service-effectiveness call for case managers.
- Preserve and define the full continuum of placement options in IDEA.

"He who defines the terms, controls the outcome..."

The New York Institute for Special Education

March 21, 1994

Congressman Major R. Owens
2305 Rayburn House Office Building
Washington, DC 20515

Dear Congressman Owens:

Enclosed, you will find the testimony that I had prepared in hopes of testifying at your Individuals with Disabilities Education Act (IDEA) hearings, on March 17th. Although, not chosen, I would like to submit my prepared text as part of the official record.

As your committee reviews IDEA I am sure that you will continue to solicit the input and expertise from parents of children with disabilities. As a parent of three children with special needs, I have had a wealth of experience in dealing with the full range of different educational settings. I believe that this knowledge would assist you greatly in your deliberation.

If such opportunities arise in the future please feel free to contact me at home, (718) 931-0761, or at The New York Institute for Special Education, (718) 519-7000, Extension #315.

Sincerely,

Olga Millan

Olga Millan, President
Parent and Staff Association
The New York Institute for Special Education

OM:jbt
Enclosure

cc: Dr. John W. McClain

Founded in 1831 as The New York Institute for the Education of the Blind

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IDEA TESTIMONY

It is indeed an honor to be speaking before you today. My name is Olga Millan the parent of four children, three of which have attended The New York Institute for Special Education in Bronx, New York. I am here today as a concerned parent as well as the President of the Institute's Parent Staff Association.

First, let me tell you a little bit about The New York Institute for Special Education. It was originally founded in 1831 as The New York Institute for Education of the Blind. In the late 1980's a name change occurred to better reflect the expanding educational services to children with different disabilities. The Institute is a private, not-for-profit, non-sectarian state supported school.

The students who attend the Institute range in age from birth to 21 years. They come from all over New York State, with the majority from the five boroughs of New York City. We have a day program, as well as a five day residential program.

There are three distinct programs at the Institute that meet the different needs of children with disabilities. Recognizing our historical commitment to children who are blind our Schermerhorn Program provides educational and support services to children who are legally blind from the ages of 5 to 21. These students participate in individually designed academic and modified academic programs that emphasize developmental independence.

A perfect example of the success in this program is Eric Randolph. Eric had a genetic eye disorder which gradually took away his eye sight during his childhood. Eric also has a severe hearing impairment. Eric managed in the public school until about junior high school. During this time an aide was necessary to take him from class-to-class. One of the biggest problems was that if

the aide was not available Eric would be placed in the school office all day. Many of his needs were never met such as mobility, braille or life skills instruction.

Mrs. Randolph then fought hard and Eric was eventually placed in the Institute. Eric became a new person with confidence in his abilities. He convinced his mobility teacher to take a trip downtown so he could apply for a summer job. One of my fondest memories of Eric was his art work, especially his beautiful pieces of sculpture. Eric graduated from the Institute last June as the valedictorian of his class. At this time he also received an achievement award from Senator Guy Velella. Today, Eric attends LaGuardia College studying computers. He travels independently to his school located in Queens, N.Y. from his home in the Bronx.

The lifestyle Eric has established would not have been possible without the strong foundation of fundamentals given at the Institute. Eric has received his wings and is on his way to accomplish many things.

Our Van Cleve Program is a special educational environment for children from 5 to 13 years of age who are both emotionally disturbed and learning disabled. This program provides a highly structured educational day and residential program, including counseling services for students and families.

My example for this program is a young boy called Hassan Yildiz. When Hassan was five years old his mother had him privately evaluated. She felt there was a problem, but wasn't really able to label it. It was more of a feeling, an instinctive one, which made her take this first step. The recommendation was that he was too close to her and should go to a school program, preferably one with a small class ratio. Ms. Yildiz enrolled him in a private nursery school for kindergarten. The class size, which was one teacher and one aide to ten children was too large

for him to handle. At the end of the year the nursery school hinted that he may have some emotional problems, however, no formal evaluation was conducted. Ms. Yildiz proceeded to register him for first grade in a Catholic school in a class of 32 children. Hassan excelled academically but began to exhibit behavior problems. Unfortunately, the teacher was new to the field and didn't understand that his peculiar behavior was an indication of more serious problems. It wasn't until April that the principal decided that he should be closely monitored and to record the disruptions. Notes began to go home complaining of his behavior.

Hassan did complete the first grade but with problems. His grades were excellent, however, his mother was concerned about all of the reports that were sent home towards the end of the year. She still hoped that Hassan would outgrow this stage.

The following September proved Hassan wasn't going through a developmental stage. Within the first two weeks of school Ms. Yildiz was called and was told that Hassan could finish the day but could not return. They were unable to handle his problems and wouldn't even consider keeping him in the program while Ms. Yildiz found another more appropriate placement. That same day Ms. Yildiz took her son to the local school district office to request an evaluation and placement. She was told it would take a few weeks. She was advised the best thing to do was to register Hassan in his local public school. They told her that all the restrictions of the Catholic school could have been a cause of his misbehavior.

Once again Ms. Yildiz registered Hassan into public school in the second grade. Soon the School Base Team (SBT) was called in to evaluate him and subsequently was referred to an outside psychologist for additional tests. By the end of the year it was determined that Hassan had a severe case of Attention Deficit Disorder (ADD). The psychologist recommended two schools, Astor School and Elton School, private Schools within New York City.

Ms. Yildiz went to her Committee of Special Education (CSE) meeting very educated regarding her son's problems. She was determined that he should go to a special school which could offer him the small class setting, and adequate adult supervision to help him learn and re-focus whenever necessary. Once in the meeting it was noted that neither Astor or Elton Schools had an available placement. The committee agreed that he should be referred to various other private schools. Ms. Yildiz was informed that she would be contacted directly by the appropriate school. Once she approved of a school she was only required to go back to the CSE to confirm her decision. Ms. Yildiz first went to the Summit School but didn't feel this was the appropriate placement. Next she went to The New York Institute for Special Education which appeared to meet all of his educational and behavioral needs.

Hassan entered third grade at the Institute when he was eight years old and graduated at age 13. At this time he entered another private school for his junior and high school education.

The Institute did not make his Attention Deficit Disorder go away but did help him understand his problem and to learn how to try to control himself. The Institute's multi-disciplinary team also helped Ms. Yildiz to learn and understand her son's condition. But for me, as for Ms. Yildiz, the Institute's most important accomplishment was that Hassan was educated. He completed all his required courses and did well. In reading Hassan was scoring near college level while his comprehension was rated at high school level. He is now in the eighth grade, so you can all see that his disability didn't have to stand in the way of a boy who is extremely bright.

There is no doubt in Ms. Yildiz's mind that Hassan would not have had succeeded in a public school or a special education program within a public school. Neither of these educational

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placement were capable of dealing so directly with this child or able to offer assistance for the parent.

The effect of a full inclusion program, that is placing him in a regular classroom for this child would have been very destructive. Today, because of the options available to his mother he will grow to be a contributing individual in society and his community.

The Readiness Program at the Institute is the one most familiar to me, as this is the program that my two older children attended, and where my youngest Daniel now attends.

Let me share some personal experiences that highlight the importance of such a school. My oldest child, Israel, was born at 26 weeks gestation. As a result of his premature birth there were many developmental and medical problems. I enrolled Israel in a Infant Health Developmental Program (IHDP) at the age of three months. Twice a week an instructor came to my home to demonstrate activities which would improve his eye-to-eye coordination or stimulate his cognitive development. At 14 months he began attending classes at their facility which included physical, occupational and speech therapy. He attended this 12 month program, from 8 A.M. to 5 P.M., until he was three years old.

He was then enrolled in the Readiness Program at the Institute. After attending a year his physical therapy was no longer necessary which surprised me since Israel has a case of mild cerebral palsy. He graduated at five years old still requiring a self contained class setting along with other services.

The CSE placed him in a Modified Instructional Setting, MIS-IV with a ratio of one teacher and aide to 10 students. He was fine the first year, but was not able to keep up once higher academic demands were place upon him. He required more one-to-one

attention than was possible in this class. Yet when his review was done last spring the SBT wanted to mainstream him. His teacher and I both agreed this would be a mistake. He was then placed in a MIS-1 class with a ratio of sixteen students to one teacher. Needless to say I am in the process of having him re-evaluated for a private school placement.

Israel had three years of his schooling wasted because of the common practice of having to fail first in the public school system before being allowed to chose other options. This is a serious dis-service to my child.

My daughter, Olga, attended the Institute for two years for a speech problem. After graduation she was able to enter the public school system in a regular setting. Although I am not pleased with her level of academics, she is a well adjusted happy girl with good verbal abilities. For her the best placement was general education in the local public school. I attribute this to the Institute which allowed her to overcome her problems and become stronger.

The Institute has accomplished much for all my children; especially for Daniel, my youngest child. My baby entered the Institute at 14 months classified as Speech Impaired and later Speech Impaired with Perversive Behavior Disorder. Finally, the classification of Autism was given. They have made every effort to educate me on how to work with Daniel.

Daniel did not want me to touch him. He would not look straight at me. He did not seem to see or hear anything around him. At first Daniel would walk over his classmates, move away if asked to join in an activity, never responded verbally, or indicated that he could hear people. It was a difficult infancy for him and me.

My son required 24 hour attention. He could not and still cannot be left alone. He has no sense of danger, little speech, and a low sensory perception; that is, he can injure himself badly and not feel it. The list goes on and on.

Yet at the Institute Daniel has made many strides. He can do puzzles and color, will sit at the table with classmates and occasionally respond to his name. He will allow classmates to join him in an activity. However, he still has a long way to go.

The Institute has given my children a strong beginning for the challenges ahead. My eldest son will one day be a contributing individual in our society along with his sister. They will be functioning persons striving toward a better life for their families and community. Daniel may contribute differently, by being able to care for himself, and as a result not be a burden to the community.

As you can see the Institute has provided my children with the academic, social, psychological and motor skills necessary to participate in an integrated society. A regular classroom setting, even with a full array of support services would have been unable to meet their needs.

As you undertake your review of the Individuals with Disabilities Education Act, I hope that you not only keep my children in mind, but all of those that have benefited from the 16] year history of quality education at the Institute.

When I hear individuals, educators, and even administrators from the Clinton administration advocate for full inclusion of <u>all</u> children with disabilities, I react with not only anger, but with disbelief and fear. I would have liked to send my children to my local neighborhood school. However, they would have received only a fraction of the support services that have been provided by the

Institute. I strongly believe that our educational system should be moving towards more inclusive schools, however, this is quite different than simply placing all children with disabilities in general education. We should all be working to develop programs and schools which provide appropriate and quality education for children with a wide range of learning needs.

It is impossible in today's society for any thinking individual to be unaware of the need to restructure our education system. As a mother of four children I am in the front line seeing how the education system has fallen apart and is failing our children shamefully. The school system has to deal with issues such as weapon control in school buildings, attacks on it's personnel; with the safety of our children no longer guaranteed. With inadequate supplies and class sizes that are too large, many of our children are lost within the system. The list of problems are just endless.

There is some hope with America 2000 and the possibilities it may offer. A beautiful dream but never the less a future dream. As the mother of four children, two which are disabled, I require an appropriate education program for my sons NOW. If that means that the more appropriate setting is a special education program in public or non-public school, than so be it. My sons cannot survive or excel in a full inclusion program. It is unrealistic to believe that a "one size fits all" program could accommodate so many children.

The Individuals with Disabilities Education Act has recognized that there may be cases where children with disabilities are inappropriately excluded from public schools. We strongly support this concept, as it is based on the individual needs of each child. If we were to fully adopt a single, mandated educational strategy this would not be possible.

The Individuals with Disabilities Education Act also very clearly promotes options for children with disabilities. We are firmly committed to these options, whether they be the public school, regular classroom, resource rooms and special classes, home instruction, hospital instruction or special schools such as ours. Each has met and continues to meet the unique and specialized needs of countless children with disabilities.

I feel confident that in your deliberations you will realize that it is this continuum of placement options that is absolutely necessary if all children with disabilities are to receive an appropriate education. We are talking about very unique and special individuals, such as my son, Daniel. If you were to go back and ask your mother when you first said the words Ma-Ma, I am sure she can remember to the day when you said it. It may have taken Daniel a few more years than most children, but thanks to The New York Institute for Special Education he has and continues to say Ma-Ma, he also has made progress in many other areas. Please don't deny Daniel his right to a full and appropriate education by changing the law.

THE NATIONAL ALLIANCE FOR THE MENTALLY ILL

The Children and Adolescent Network of the National Alliance for the Mentally Ill (NAMI-CAN) is pleased to submit testimony relevant to the reauthorization of the Individuals with Disabilities Education Act. The Children and Adolescent Network (CAN), as a legitimate branch of its parent organization, the National Alliance for the Mentally Ill (NAMI), attempts to advocate *for families* who have children with severe mental illness and *for children* with such illnesses whose education is governed by the provisions of IDEA. Since its formation, NAMI-CAN has advocated for educational, medical, vocational, and rehabilitative services for children and adolescents with neurobiological disorders (NBDs) including but not limited to: childhood schizophrenia, autism, Tourette's syndrome, unipolar depression, bipolar affective disorder, pervasive developmental disorders, obsessive compulsive disorder, attention deficit hyperactivity disorder, and anxiety disorders.

We are offering this testimony primarily to make clear our position that children with NBD are a separate population from children with SED. We request that IDEA be amended to create a category separate from SED for children and adolescents who suffer from NBDs. The regulations interpreting IDEA now define SED as "an inability to learn that cannot be explained by intellectual, sensory, or health factors." Clearly children who suffer from NBD have an illness that explains their episodic inability to learn. Our recommendation that a separate category for NBD children be established would place neurobiological disorders such as those listed above on a par with specific learning disabilities, autism, and traumatic brain injury, each of which the current law recognizes as a category separate from SED.

We believe that unless the federal government takes the initiative to require a more aggressive policy regarding the requirement that states identify and appropriately serve children with neurobiological disorders, our children will continue to slip through the cracks as "invisible children" and not receive a free, appropriate, public education. More often than not, they will continue to be harmed by the education they receive. The change in the law begins with a change in the definition of SED students and the addition of a neurobiological-disorder-education category, but it must be followed by reworking the language in IDEA regarding (1) evaluation, (2) IEPs, (3) placement, (4) least restrictive environment, (5) state-approved schools, (6) compensatory education, (7) the stay-put provisions of IDEA (so that such provisions do not preclude parents from acting in a crisis), (8) related services, (9) the tracking system used to count data on student outcomes, (10) transition programs, and (11) extended school year qualification standards so that the kinds of educational services our children need can be readily identified and delivered.

Parents must have choices from an array of services to insure their children are *included* in the educational system and that never again will a child reach adulthood without education. It is important that parents continue to have the option to use IDEA funding to make placements in special education facilities other than a mainstream classroom, including residential treatment centers. It is also important that Congress insist that existing residential treatment centers be staffed entirely with personnel trained in the latest knowledge available from the neurosciences about the management of NBD. *The nature of*

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these illnesses is such that the appropriate educational setting for some of the children afflicted by them must be highly structured and low in stimulation.

We advocate that the law be changed to require the education system to provide compensatory education to a child who is beyond age 21 and who, because of a cyclical brain disorder, has not been able to obtain a high school diploma, but who has subsequently become stable enough to earn one. The nature of NBD is episodic so that some children are not able to learn at one point in their life but later become able. It is imperative that we recognize this difference in NBD children and guarantee these children the right to compensatory education. Without this guarantee, these children become "stuck in time," not having passed important developmental and educational milestones. This right to compensatory education after age 21 should be available without requiring that parents go through a due process hearing to obtain it.

In the past, NAMI leadership and members have offered to the U.S. Department of Education commentary on and recommendations for change in the regulatory definition of "children with serious emotional disturbance" under IDEA. NAMI supported a change in the definition only if "children with neurobiological disorders" were "specifically identified as eligible for services under IDEA." (See letter to Ms. Martha Coutinho from NAMI, May 10, 1993.)

Our children are different in major respects from the category of seriously emotionally disturbed children. They suffer from bona fide medical maladies, which interfere with their education. These maladies do, in most cases, have recognizable patterns of clinical symptoms, scientific tests for diagnostic accuracy, and accepted standards for medical treatment.

Many parents in the NAMI network have viewed with enthusiasm the explosion of information in the neurosciences that has added more and more weight to the claim that the individuals for whom we advocate are suffering from what can more correctly be termed "neurobiological disorders." Moreover, because we do not recognize our children in any of the descriptions under the heading "Handicapped Children" or under the definition of "children with disabilities" in IDEA (Section 101. Definitions), we believe that the failure to change the language of IDEA may be, with the passage of time, creating a *most serious and systematic civil rights exclusion and violation*. Our children are being denied equal protection rights under IDEA by being denied a free, appropriate, public education (FAPE). This denial is being sanctioned by the categorical language used and by the imperfections in the procedural mechanisms mandated by IDEA.

Much harm has resulted from the failure to include "neurobiological disorders" as a specific class of educational disabilities that qualifies children for services under IDEA. For the student needing special education services, medical evaluations and management strategies often carry with them implicit assumptions about the management of a neurobiological disorder, and educators are not trained to translate these implicit assumptions into educational or behavior-management strategies. This factor alone complicates placement, IEP and related-services planning, and LRE rights. Medical diagnoses (especially by qualified neurobiologically trained psychiatrists), medical support services, recommendations, etc., must

be translated into the language of IDEA, a task most educators are unprepared to undertake, and medical evaluations must be given more significant weight than they often currently are. In addition, medical evaluations must be financed, and a way must be found to prevent children from becoming lost in the"politics" of and disputes over funding mechanisms for independent evaluations.

For our children *it is absolutely necessary that medical involvement go beyond evaluation.* If a child with NBD is to be *available for education*, there must be consistent and ongoing interaction between medical and educational personnel. The medical input must be available throughout the course of education. This input is necessitated by the fact that changes in medication, in behavior-management strategies, and in environment must be predicated upon people sensitized to the profiles of behavior presented by NBD children. The language of IDEA 1401(E)17 states that "medical services shall be used for diagnostic and evaluation purposes only..." and therefore ensures that large numbers of our children will be discriminated against with regard to being available to receive a free, appropriate, public education. To reiterate, educating NBD children requires ongoing interaction between medical and educational personnel. Titrations in medication, for example, are often initiated on a daily basis. Many medications are ordered p.r.n. (as needed) to control symptoms of an illness, and those in a position to observe behavior must be able to make medical judgments about increasing/decreasing/adding medication, especially in "crisis" situations.

Because there is no separation of the various categories of children served under the rubric "seriously emotionally disturbed," our children are almost always inappropriately served by the structure of services in place for SED children in most public school systems, a structure which thus denies them a FAPE. Perhaps a review of an actual case history will help to illustrate this point:

> Words alone cannot convey the tragedy of a family in Alabama whose young son was stricken with bipolar illness at the age of 14. Neuroscience has advanced enough to tell us that when bipolar illness first strikes a child, its medical management can be uncomplicated for those who respond to lithium. However, when improperly managed in an educational or other environment, it can be rekindled easily. In the case of this Alabama student, the school system attempted, *against good medical advice, and sworn testimony containing solemn warnings about the dangers*, to mainstream him in the regular educational environment in a variety of inappropriate school placements. Each time, his illness was rekindled, necessitating eleven hospitalizations in a few short years. Now nine years later, he is still without a high school education. He is stabilized, is living with his parents, and receiving Medicaid. He is above-average in intelligence. An appropriate educational placement very likely would have enabled this student to become a productive citizen. Not only has the "rekindling" process prevented him from becoming educated, it has harmed him medically by worsening the course of his illness since he requires higher quantities of medication for stabilization.

No epidemiological studies have been done of the prevalence of NBD in children. Therefore, we have no accurate data on how many children there are with severe neurobiological illnesses. Considering the fact that suicide is the second leading cause of death in the 14-18 age group, we should pause to consider the consequences of our failure to identify children and adolescents with disabling brain disorders.

Even if we had adequate epidemiological studies of the statistical frequency of childhood neurobiological disorders, we could not relate these studies to those tracking systems in place under IDEA, since students with neurobiological disorders are usually tracked under the category of "SED," given the language of IDEA as it is currently written. Thus, we would never have any reasonable "statistical benchmark" by which to compare a state educational agency's performance in identifying and serving an adequate number of children with the various neurobiological disorders mentioned above.

One cannot possibly imagine the harm suffered by a child with a severe neurobiological disorder under present law as it is implemented. Educating a student with childhood schizophrenia or severe unipolar depression or bipolar disorder or obsessive compulsive disorder requires a very fluid medical-educational model for the delivery of instructional services. One must be able to switch rapidly from a medical to an educational paradigm when educating these children, and in point of fact, for many of these children educational-medical requirements for service delivery are inseverable. The uniformity and conformity of the behavior-management strategies designed to manage SED or behaviorally disordered children are *absolutely inappropriate for children with NBD*. Many of the behaviors of these children that often interfere with learning *are not behaviors which can be modified with routine classroom-management strategies*. Thus children with neurobiological disorders frequently find themselves being educated under inappropriate IEPs (Individualized Educational Plans) that are not driven by modern medical knowledge of their condition, find themselves in an environment that meets none of the appropriate criteria for a least restrictive environment (LRE), find themselves receiving little or no "related services" relevant to the specific disability, and so on. In fact, all evidence indicates that children with NBD have higher dropout rates, lower college attendance rates, higher unemployment rates, less rehabilitative-service use rates than most groups of disabled children (See *All Systems Failure*). And since most states do not require compensatory education beyond age 21, many children with NBD, even when they want to attend high school and obtain a diploma, have no legal right to do so.

For many children with disabilities a "crisis" in the stage of their illness often requires medical intervention, sometimes hospitalization. Children with NBD are no different in this regard. A school system that is not geared to deal with the start-stop nature of some of the cyclical illnesses of this population is one that will guarantee that these children will "fail and fail big when they do," and not be provided a free, appropriate, public education.

Parents who act unilaterally and place children who are in a state of crisis in private schools out of sheer desperation because the school system is failing to appropriately educate these children are usually not well-informed enough to negotiate contractual transferences of IDEA rights to

private placements, and such parents need continuity in placement advice even when they disagree with school officials over placements which appear to be harming their children. The Department of Education is not currently capable of giving such advice on the federal level, and it is not in the interest of LEAs or SEAs to give such advice. At a minimum, the regulations should include guidelines to parents who make unilateral placements in private schools to negotiate contractually guaranteed due process rights for their children so that they are not inappropriately educated/disciplined/evaluated when they exhibit behavior that is a manifestation of their medical condition.

Under IDEA, Congress rightly continued the distinction between first priority children and second priority children who needed services. First priority children means children with disabilities who are not receiving an education, and second priority children means those with the most severe disabilities who are receiving an inadequate education. We have anecdotal evidence and considerable statistical warrant to argue that vast numbers of children with neurobiological disorders belong among both priority groups and that in large numbers, they are not being identified or served. Perhaps just as important is the fact that where they are being served, they are being served inappropriately and not being provided a free, appropriate, public education.

NAMI

May 10, 1993

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1994 ANNUAL CONVENTION
Miami, Florida
July 21-24, 1994

Ms. Martha Coutinho
U.S. Department of Education
400 Maryland Avenue, S.W.
Switzer Building, Room 3522
Washington, DC 20202-2641

Dear Ms. Coutinho:

I am writing in behalf of the National Alliance for the Mentally Ill (NAMI) and its Children and Adolescent Network (NAMI CAN) to comment on your "notice of inquiry" concerning possible changes to the regulatory definition of "children with serious emotional disturbance" under IDEA. NAMI is a national grassroots organization with 140,000 members who, for the most part, are families of persons with severe mental illness as well as those persons themselves.

NAMI supports a change in the definition only if "children with neurobiological disorders" are specifically identified as eligible for services under IDEA. It is our preference that this be specified as a distinct category within IDEA. If this is not possible, then we request that "neurobiological disorders" be added to the proposed definition so that it reads "children with emotional, behavioral or neurobiological disorders".

It has been the experience of our members throughout the country that school systems frequently categorize all children and adolescents who manifest dysfunctional or inappropriate behaviors in schools as "seriously emotionally disturbed", regardless of etiology. Consequently, children with neurobiological disorders such as schizophrenia, affective disorders, anxiety disorders, and other disorders linked to the brain are frequently placed in the same classes and offered the same services as children whose problems relate to social, familial or other environmental factors.

Without suggesting that one group of children should be prioritized at the expense of the other, it is our position that the educational and related needs of children with neurobiological disorders differ significantly from those of children whose problems relate to other, non-physiological factors. Recognition of neurobiological disorders as a distinct category under IDEA is essential if we are to develop Individualized Educational Plans (IEP's) which are truly tailored to address the unique needs of children who suffer from them.

The existence of the broad category of "serious emotional disturbance" may well

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have traditionally reflected a desire on the part of schools and educational personnel to avoid prematurely "labeleling" and stigmatizing children. However, in the case of children with neurobiological disorders, this hesitance to diagnose has too often resulted in failure to provide appropriate services for children who suffer from them. NAMI strongly believes that schools should strive to accurately diagnose children with neurobiological disorders as early as possible and consequently to provide children with these disorders with educational and supportive services consistent with their individualized needs.

Recently, there have been significant scientific advances in identifying and treating children and adolescents with neurobiological disorders. (See, e.g., Peschel, et al, Neurobiological Disorders in Children and Adolescents: New Directions for Mental Health Services, Jossey-Bass, 1992). These advances raise hope that treatments for these most devastating brain disorders will continue to improve. If this is to occur, it is imperative that advances occur also in developing methods for educating children who suffer from these disorders so that they will be afforded opportunities to develop in accordance with their individual potentials. The identification of neurobiological disorders within IDEA represents an important step in this regard.

I appreciate the opportunity to comment on this important issue. Please contact Ron Honberg or myself at 703-524-7600 with any questions.

Sincerely,

Laurie M. Flynn

Laurie M. Flynn
Executive Director

LMF/rsh

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ISBN 0-16-044876-X